HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA): CONFIDENTIALITY AND PRIVACY FROM THE PERSPECTIVES OF THE CONSUMER AND THE PHYSICIAN

by

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Abstract

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) establishes national medical data standards for administration, security, and privacy. This study examined differences in the perceptions of physicians and consumers of care (patients) as they relate to the HIPAA Privacy Rule. The research determined that patients and physicians differ in their perceptions of the HIPAA Privacy Rule. The research also revealed that patients and physicians differ in their perceptions regarding confidentiality and disclosure. In addition, the study examined whether possible ambiguity of the HIPAA guidelines adversely affects the quality of patient care of the consumers (patients) as a result of the interpretation and implementation of the regulations by healthcare providers. The study concluded that physicians and patients have different perceptions regarding the impact of HIPAA and its effect on the quality of patient care.

Dedication

To my late grandmother, Elizabeth Oliver; my late parents, Doris and Marshall Jones; and my late brother, who instilled in me the importance of education at an early age.

Acknowledgments

I would like to acknowledge my mentor, Dr. Rubye H. Braye, for her guidance and inspiration. I would like to acknowledge my committee members who gave me invaluable assessment. In addition, I would like to acknowledge Dr. Sandra Braxton for her encouragement. Finally, I would like to acknowledge my husband, children, and sister for their unwavering support and sacrifice in order for me to attain my goal.

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CHAPTER 1. INTRODUCTION

Introduction

The Health Insurance Portability and Accountability Act (HIPAA) provides for portability of health insurance from employer to employer; standards for transmitting health information in writing, orally and electronically; and methods for assuring the security, confidentiality, and privacy of personal health information. In other words, the goal of HIPAA is to ensure that a patient's health information is not misused by health care providers, business associates, and insurance companies or their employees. According to Pace and Staton (2005), the legislation was written to accelerate the development of data standards for the transmission of health information; however, it was quickly apparent that transmitting health information electronically presented hazards that required special attention. The HIPAA legislation, originally passed in 1996, was amended several times over the intervening years, and was finally implemented in 2003 (Swartz, 2003). In the years of its development and since its implementation, HIPAA has raised deeply fundamental issues for health care providers, insurers, employers, policy makers, researchers, and those most concerned with patients and consumers of healthcare services and their families.

The delivery of healthcare in the United States is changing considerably as a result of legislative adjustments, the first of which became effective on October 16, 2002.

According to Kiel (2005), this was the initial implementation date of the Transactions and Code Sets Rule of Health Insurance Portability and Accountability Act, followed by HIPAA's Privacy Rule and HIPAA's Standard Unique Employer Identifier, implemented on April 14, 2003, and April 21, 2005, respectively. Kiel further stated that these 4 existing rules are only 4 of the 11 parts of HIPAA. The remaining 7 parts are in various stages, ranging from being fully written to mere ideas.

Background of the Study

According to Slutsman (2004), until recently, health information held by the private sector was protected by an inadequate patchwork of state laws, common law, and professional codes of ethical conduct for clinicians. HIPAA represents an effort to impose a minimum, uniform standard of privacy on healthcare providers, which includes physicians and healthcare organizations. However, Hollister (2003) suggested that the overriding goal of HIPAA was to increase the number of persons who have and maintain health insurance. In addition, HIPAA includes provisions to combat waste, fraud, and abuse in the healthcare system and to assure for privacy, security, and standardization of electronic transmission of health information.

According to L. Jones (2001), these standards are intended to set guidelines for costs, technical capabilities, and training required for records systems used to maintain health information. Additionally, they are to establish safeguards to ensure the integrity and confidentiality of the information. They will protect unauthorized uses or disclosures and against any reasonably anticipated threats or hazards to the security or integrity of the information. Finally, they will ensure healthcare providers, business associates,

organizations, and insurance companies and their respective employees comply with the requirements.

Parker (2003) further affirmed that HIPAA was passed by Congress in 1996 to allow patients easier access to their medical records and to limit others' ability to get such information. It took the government 7 years to write the regulations for enforcing the law. Nonetheless, some of the rules have been interpreted in different ways by healthcare providers, insurers, as well as healthcare consumers. HIPAA is most often recognized today for its three main provisions—promoting electronic transmission standards for claims data, and regulating both the privacy of electronic medical records and the security of medical data storage and transmission. HIPAA changed the U.S. healthcare landscape, in some ways for the better and in some ways for the worse (Conn, 2006). As a result, the dramatic changes in the healthcare delivery and administration over the past several decades have resulted in increased patient concerns about privacy (Benefield, Ashkanazi, & Rozensky, 2006). Benefield et al. further suggested that HIPAA contains detailed practice standards for maintaining patients' privacy and potential punitive actions in the case of violations. For those in private practice, these guidelines have implications for day-to-day practice, but have potentially even greater effect when providing care for patients within highly regulated, organized healthcare environments, such as hospitals and health science centers.

Lo, Dornbrand, and Dubler (2005) indicated much of the controversy and confusion over the HIPAA regulations concern what are referred to as "incidental" disclosures. Some interpretations of the privacy regulations could limit essential communication and compromise good patient care. Many misconceptions arise from gaps

in the regulations. These gaps are filled by professional judgment buttressed by ethical guidelines. Confused healthcare providers remain worried about breaking the law inadvertently, according to Margaret M. Davino, JD, a healthcare attorney specializing in HIPAA. Many healthcare providers are unsure as to with whom they can now share patient information (Wilson, 2006).

Salem and Pauker (2003) suggested although the goal of HIPAA is to protect patients' privacy and rights, such protections, if either misunderstood or overzealously applied, could impede necessary communication and thereby negatively affect patient care and safety. Walfish and Sharp (2005) indicated the HIPAA security and privacy requirements were specifically designed using guidelines rather than hard-and-fast standards. Though the protection of health information is important, there are some very legitimate reasons to access medical information, such as for public health purposes, research, and to improve care (Pollio, 2005).

Lo et al. (2005) took the position that many physicians regard these regulations as a bureaucratic impediment to patient care rather than an advance in protecting confidentiality. They further stated much of the controversy and confusion over the HIPAA regulations concern "incidental" disclosures. This refers to occurrences in the course of good patient care where communications among healthcare workers treating the patient may be seen or overheard by someone else.

Another complication was noted by Pollio (2005). It is presumed that patients understand the notices they receive from their healthcare providers. The Department of Health and Human Services has made it clear that it is not the providers' responsibility to ensure that patients actually understand or even read the notices given to them. Moreover,

the notices may be written in such a way that they are unclear to patients, even if they choose to read the notices given to them to sign. For example, in their notice of privacy practices in the commitment to privacy, CorVel Corporation (2003) stated they are

> Committed to protecting the privacy of your protected health information (health information). Health information is information that identifies you and relates to a physical or mental condition, or to the provision or payment of health services for you. CorVel also pledges to provide you with certain rights related to your health information. By this Notice of Plan's Privacy Practices (Notice), CorVel informed all that it has the following legal obligations under the federal health privacy provisions contained in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the related regulations (federal health privacy law):
>
> To maintain the privacy of your health information
>
> To provide you with this Notice of its legal duties and privacy practices with respect to your health information; and
>
> To follow the terms of this Notice currently in effect.
>
> This Notice also informs you how CorVel uses and discloses your health information and explains the rights that you have with regard to your health information maintained by CorVel. For HIPAA purposes, CorVel is a hybrid entity. This means that HIPAA only applies to certain lines of service or "health care components" and not all of the lines of service offered by CorVel. Specifically, this Notice is directed care services such as independent medical examinations, durable medical equipment, prescription drug network and certain case management services. You will receive a separate Notice of Privacy Practice if you are receiving imaging services. (p. 1)

Finally, Wilson (2004) indicated HIPAA itself is not the problem, inaccurate interpretation of the law is. Conversely, Pollio (2005) suggested that some of the confusion stems from the vague language in some of the key provisions of the Privacy Rule. For example, covered entities may disclose only the minimum necessary to satisfy the purpose of disclosure. Anticipating the minimum necessary disclosure would be extremely difficult, creating significant burdens in even the most routine daily processes, perhaps leading to reduced quality in patient care. HIPAA regulations are written in ambiguous terms, which lends itself to a multitude of interpretations that could adversely affect consumers or patients.

Statement of the Problem

The problem is that the lack of standardization of the HIPAA law lends itself to different interpretations of the rules, which may result in nonuniform applications of the guidelines. There is much confusion among healthcare professionals regarding the application and interpretation of the HIPAA privacy regulations pertaining to protected patient health information. As a result, the healthcare consumers or patients as well as healthcare providers can be adversely affected. It is expected by some that the overall effect of HIPAA will be on the quality of healthcare that patients receive. Stein (2003) suggested that the overwhelming majority of problems appear to be the result of misunderstanding of the law's requirements by erring on the side of withholding information to avoid inadvertently violating the restrictions.

Purpose of the Study

The purpose of this research was to determine consumers' and healthcare providers' perspectives of the privacy regulations as well as any adverse effects on patient care as a result of the HIPAA legislation. As a legislative mandate that was not enacted by Congress, HIPAA is a reflection of the national will that now requires interpretation by each "covered entity." Given the severity of the penalties for violating the HIPAA guidelines, including significant fines and criminal prosecution, most covered entities likely will interpret the regulations in the most conservative manner (Califf & Lawrence, 2003). For example, some facilities have become so restrictive, they are either not releasing any information or are mailing requested information rather than faxing it

(Wilson, 2004). This quantitative study focused on the privacy aspect of HIPAA. This study was based on the following research question:

Research Question

Do the perceptions of healthcare providers regarding privacy affect patient care?

Hypothesis

$H1_0$: There is no difference in the perception of HIPAA between providers and consumers of care.

$H1_A$: There is a difference in the perception of HIPAA between providers and consumers of care.

Significance of the Study

The various interpretations of the HIPAA guidelines are contributing to delays in providing patient information to healthcare providers and other parties. Wilson (2004) stated that HIPAA was created so there would be a national norm regarding healthcare information, not so that pertinent information would be withheld in emergencies or for patients who are unable to give consent. According to Lo et al. (2005), a news story reported that physicians were not providing information to patients' families because of misunderstandings about the privacy regulations. Therefore, providing the appropriate regulatory agencies with the effect of HIPAA as perceived by the healthcare providers and consumers will perhaps motivate the agency to standardize the HIPAA guidelines, resulting in uniform interpretation.

Definition of Terms

Business associate. As defined by the Office for Civil Rights (OCR, 2003):

> A person or organization, other than a member of a covered entity's workforce, that performs certain functions or activities on behalf of, or provides certain services to, a covered entity that involve the use or disclosure of individually identifiable health information. (p. 3)

Confidentiality. As defined by Slutsman (2004):

> The respectful handling of information disclosed within relationships of trust, such as healthcare relationships, especially as regards further disclosure. Confidentiality in healthcare is closely related to informational privacy and the two terms are often used interchangeably; however, they refer to differing ideas. Confidentiality comes into play once a patient has disclosed information to another party, an information trustee, with the understanding that the information will be used for a particular purpose. (p. 6)

Consumer/Patient. One and the same for the purposes of this research, *patient* is defined as "a person who is ill or who is undergoing treatment for a disease entity," according to *Dorland's Illustrated Medical Dictionary* (2003, p. 1386).

Consumer of care/Patient. One for the purposes of this research which is based on age, ethnicity, gender, marital status and employment status.

Healthcare clearinghouses. As defined by the OCR (2003): "entities that process nonstandard information they receive from another entity into a standard (i.e., standard format or data content), or vice versa" (p. 3).

Healthcare providers. As defined by the OCR (2003): includes all

> Providers of services (e.g., institutional providers such as hospitals) and providers of medical or health services (e.g., non-institutional providers such as physicians, dentists, and other practitioners) as defined by Medicare and any other person or organization that furnishes, bills, or is paid for health care. (p. 2)

Health information.

> Information that relates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an individual. (Kamoie & Hodge, 2004, p. 119)

HIPAA regulations. Kibbe (2001) indicated there are actually three sets of standards: "transactions and code sets, privacy, and security" (p. 2). Privacy and security are closely linked, so it is important to understand the difference.

Informational privacy. As defined by Slutsman (2004): "the claim of individuals, groups, or institutions to determine for themselves when, how and to what extent information about them is communicated to others."

Physician/Healthcare provider. For the purpose of this research, these terms are one and the same; "(a) an authorized practitioner of medicine, as one graduated from a college of medicine or osteopathy and licensed by the appropriate board; (b) one who practices medicine as distinct from surgery," according to *Dorland's Illustrated Medical Dictionary* (2003, p. 1434).

Privacy. As defined by Kibbe (2001): "the patient's right over the use and disclosure of his or her own personal health information" (p. 2). *Privacy* "includes the right to determine when, how and to what extent personal information is shared with others" (Kibbe, p. 2). The HIPAA privacy rules grant new rights to patients' access to and control the use and disclosure of their personal health information.

Protected health information (PHI). As defined by Kibbe (2001): the "HIPAA term for health information in any form (i.e., paper, electronic or verbal) that personally identifies a patient" (p. 2).

Security. As defined by Kibbe (2001):

> The specific measures a health care entity must take to protect personal health information from unauthorized breaches of privacy, such as might occur if information is sent to the wrong person in error. Security also includes measures taken to ensure the integrity of personal health information. (p. 2)

Assumptions and Limitations

This research assumed that the healthcare providers and patients would complete the survey with integrity.

The limitations of this research were that the survey was limited to physicians as healthcare providers in private practice. In addition, the survey was limited to private patients in physicians' offices or clinic settings.

Nature of the Study

The researcher surveyed healthcare providers and consumers of care using a quantitative research methodology. To accomplish this research, the researcher surveyed private practice physicians and consumers. The survey, in the form of a questionnaire, was conducted in clinics as well as private practice physicians' offices in Pontiac, Michigan. The research study identified how healthcare providers and consumers perceive the effect of HIPAA.

Bryman and Bell (2003) stated that

> Quantitative research can be construed as a research strategy that emphasizes quantification in the collection and analysis of data that
> 1. Entails a deductive approach to the relationship between theory and research, in which the accent is placed on the testing of theories;

2. Has incorporated the practices and norms of the natural scientific model and of positivism in particular; and embodies a view of social reality as an external, objective reality. (p. 25)

According to Cooper and Schindler (2003), the great strength of the survey as a primary data collecting approach is its versatility. It does not require that there be a visual or other objective perception of the information sought by the researcher. Abstract information of all types can be gathered by questioning others.

Organization of the Remainder of Study

The remainder of the study consists of four additional chapters. Chapter 2 includes a review of the literature in reference to HIPAA privacy and confidentiality from the perspectives of consumers and healthcare providers. Chapter 3 describes the methodology, sampling design, and data collection process. Chapter 4 consists of a pilot study and an analysis of the survey results. Chapter 5 consists of the conclusions and recommendations.

CHAPTER 2. LITERATURE REVIEW

Introduction

This chapter has four sections. The first section details the background of HIPAA. The second section addresses the privacy issues of HIPAA. The final sections cover confidentiality and disclosure requirements.

HIPAA provides for portability of health insurance from employer to employer; standards for transmitting health information in writing, orally, and electronically; and methods for assuring the security, confidentiality, and privacy of personal health information. The legislation, originally passed in 1996, and amended several times over the intervening years, was finally implemented in 2003, according to Swartz (2003). In the years of its development and since its implementation, HIPAA has raised deeply fundamental issues for healthcare providers, insurers, employers, policy makers, researchers, and, most prominently, for patients and consumers of healthcare services and their families. The goal of HIPAA is to ensure the protection of confidential health information through having appropriate security systems to guard against unintentional disclosure of that information (Erlen, 2007).

The HIPAA legislation is national in scope, sweeping in its coverage, and far-reaching in its implications, and thus concerns a wide range of stakeholders, as is evident in what has been written about it in the last 8 years. Entering “HIPAA” into a commonly-

used database (i.e., EBSCO) resulted in thousands of entries, from a wide range of popular, professional, and scholarly publications. Just a brief survey of the types of publications that have published articles about the HIPAA legislation in 2005 alone gives a picture of the range of the interest in the legislation.

Within the healthcare industry, which includes not only healthcare providers but, importantly, the entities that are associated with them in a business sense, articles regarding HIPAA appeared in the provider publications such *as Healthcare Executive, Hospitals & Health Networks*, *AHA News*, *Nursing Home Long Term Care Management*, *Trustee*, *Modern Healthcare*, *Nursing Management*, and *Physician Executive*, among others. Within the healthcare provider category, there are a number of specialty journals, including those focused on financial issues within the industry, in which articles appeared, such as *Healthcare Financial Management*, *Healthcare Registration*, *Healthcare Collector*, and *Healthcare Biller*.

Among professionals concerned with other aspects of the healthcare industry, including the technology related to medical information gathering and transmission, articles appeared in such publications as *Health Management Technology and Health Care Manager*. There was a great deal of interest on the part of employers, as evidenced by articles appearing in *Employee Benefits Plan Review*, *Medical Benefits*, *HR magazine*, *Employee Benefits Journal*, *Benefits Law Journal*, *Journal of Deferred Compensation*, and *Benefits Quarterly*.

Shortly after the HIPAA regulations were published, there was some confusion within the healthcare community about whether HIPAA regulations would prevent electronic forms of communication between physicians and their patients. In fact, one of

the goals of HIPAA is to facilitate increased use of electronic channels for the delivery and operations of healthcare (Taliaferro, 2005). Therefore, technology professionals were also extremely interested, and articles about the HIPAA legislation appeared in *Insurance & Technology*, *Network World, and Security Management. eWeek, Productivity Software, Information Management Journal, Information Week,* and even *Computer Reseller News.* An additional group of interested parties, who are also business associates of healthcare organizations, showed their concern in articles appearing in such publications as *Managed Care Weekly Digest*, *Managed Healthcare Executive*, and *Drugstore News*.

In the business press, much attention was paid to the implementation of HIPAA. As Swartz observed

> Businesses demand the benefits of a technology-enabled world along with the relative anonymity, or privacy, that the pre-technology world provided. The government's response to that paradox is regulation that balances business' need for increasingly detailed data with the public's demand for privacy. (2003, p. 26)

The "balance" referred to here is a recurring theme in all of the literature on the subject of the regulations, as discussed throughout this review.

The reason that business stakeholders are so interested in the HIPAA legislation in that healthcare organizations share information with a variety of business associates ("any entity working in partnership with the covered entity and receiving health information from the covered entity or working for or on behalf of the covered entity" [Swartz, 2003, p. 28]) who are also subject to HIPAA legislation, such as "vendors, consultants, lawyers, auditors, clearinghouses, billing firms, and record storage" companies (Swartz, p. 28). Hilger (2004), for example, writing in *Benefits Quarterly,* addressed the HIPAA-related concerns of employers who administer health plans using a

contracted vendor for record keeping who qualifies as a "business associate" under HIPAA regulations. While life insurers, employers, schools, public agencies, and other organizations are perhaps not directly affected by the legislation, they may still feel its impact, as discussed in following sections. All of these impacts, in a ripple effect, eventually reach the consumer of healthcare services.

Articles in newspapers, news magazines, and the popular press make clear concerns about the potential direct effects of the HIPAA legislation on consumers of healthcare services. For example, Nagourney (2000) addressed the security of health-related Internet sites, asking, "If a site is all about your health, who else might be peeking?" (p. H16); the next year, Hafner (2001) described consumers' means of remedy if they believed their health information privacy had been violated; and another discussed consumers' rights with regard to the privacy of information disclosed to insurers (Fried, 2001).

Coverage of the implementation of the HIPAA legislation in the *New York Times* in the spring of 2003 featured such headlines as "Health System Warily Prepares for the New Privacy Rules" (Pear, 2003), "The Privacy Practice: Sign Here and Here" (Flinn, 2003), and "Sorry, That Information is Off Limits: A Privacy Law's Unintended Results" (Tarkan, 2003). By contrast, some publications, such as *U.S. News & World Report* and *Modern Healthcare,* took a more skeptical perspective: "A Healthy Dose of Privacy: A New Law Tries to Protect Patients' Medical Records—But Has Glaring Gaps" (Hawkins, 2003), "Protection in the Eye of the Beholder: Courts Send Mixed Messages About the Sanctity of Medical Files" (Taylor, 2004) and "The HIPAA Headache" (Morrissey, 2004).

Much of what has appeared in the popular, professional, and scholarly press since the implementation of the HIPAA regulations in 2003 has been an attempt to explain the regulations to specific audiences, such as "HIPAA and Its Impact on Pharmacy Practice" (Giacalone & Cacciatore, 2003), "The HIPAA Privacy Rule and HR/Benefits Outsourcing: Does the Business Associate Label Belong on Your Record Keeper?" (Hilger, 2004), "Privacy and Security Under the Health Insurance and Portability and Accountability Act" (Miller & Pollak, (2003), and "HIPAA Privacy and Security: Developing a Culture of Privacy" (Pickering, 2003).

In an attempt to describe the reasons why the confidentially of medical records is such a controversial topic that Congress was unable to pass legislation for about 8 years, Donna Shalala, then Secretary of Health and Human Services, stated: "Federal law does more today to guarantee the privacy of our choices of video rentals than it does our personal medical histories" (as cited in Hussong, 2000, p. 453). In her review of the literature, Hussong found that strict legislation was generally supported by physicians, patients, and healthcare consumer advocates, while institutions like insurers, hospital systems, the American Medical Association, and law enforcement have generally been critical. Mental health professionals, among others, have been ambivalent toward the legislation.

There has been an assortment of often overlapping or even contradictory legislative actions in the last 10 years, among them the core Department of Health and Human Services regulations, the Privacy Commission Act of 2000, the Health Care Personal Information Nondisclosure Act of 1999, the Medical Information Privacy and Security Act of 1999, the Medical Information Protection Act of 1999, the Medical

Information Protection and Research Enhancement Act of 1999, the Health Information Privacy Act of 1999, and the Personal Medical Information Protection Act of 1999. As of 2000, Hussong found that the following loopholes, which are also consumer and provider concerns, had been identified: federal legislation at one time covered electronic medical records but not paper ones (that loophole was closed with the final HIPAA Rule); patient access to their medical records; lack of sanctions when organizations misuse sensitive medical information, such as that pertaining to mental health and substance abuse; federal legislation often preempts state legislation; and federal legislation does not include a private right of action and does not apply to privately funded research. Some of these loopholes were addressed as the HIPAA legislation assumed its final form, but there are still many gaps that are confusing—to healthcare providers, insurers, and healthcare consumers alike.

The final security rule makes a clear distinction between privacy and security by defining *security* as covering electronic protected health information (PHI) and *privacy* as covering all other PHI (Brown, 2006). Brown further stated that although privacy and security rules are distinct in that security covers electronic data and privacy covers nonelectronic data, physical security is important to both. In other words, how and where the protected health information is stored is a concern for both patients and healthcare providers.

A number of researchers have observed that patient privacy and the confidentiality of health information were already being eroded without the implementation of HIPAA. As Deshefy-Longhi, Dixon, Olsen, and Grey (2004) pointed out, the increasing use of computer and video technology in medicine, as well as the

increase in medical research, greatly expanded the number of people with access to confidential information.

In addition, healthcare organizations themselves have been changing in essential ways, primarily in the direction of *integration*, which means that formerly independent healthcare providers are now integrated into large health systems and networks that include many large and small providers, medical schools, ancillary services, technical support organizations, and similar providers of associated services. The advances that managed care organizations have made in recent years have also greatly increased the exposure of health information to a wide range of business associates, all of whom have potential access to confidential information. Deshefy-Longhi et al. cited the example of managed care organizations that established their own formularies of approved prescription drugs, directly linking pharmaceutical manufacturers and suppliers to the organization's prescription information on patients.

Health Insurance Portability and Accountability Act Framework

To date there has been very little empirical research based on conceptual or theoretical frameworks specifically related to the effect of the HIPAA regulations, perhaps because they are yet too new. Even so, such frameworks exist, and are appropriate for empirical investigations. The concept of *privacy*, for example, has long been considered conceptually by sociologists, psychologists, ethicists, and philosophers. More recently, this concept and others related to it, such as *confidentiality*, have attracted the interest of scholars in the emerging field of *medical informatics*, the study of the application of computer and statistical techniques to the management of health and

biomedical information. These scholars have begun to develop the conceptual basis for *digital identity* as it relates to the confidentiality and security of electronic information collection, storage, access, and transmission.

Concepts related to the doctor-patient relationship—in addition to privacy and confidentiality—include *trust*, which many patients, medical professionals, and researchers view as essential to the relationship; and *autonomy*, which has been considered in the context of patient-as-consumer of health-related services. An additional concept discussed here, the *law of unintended results*, is included because it is frequently invoked in examinations of HIPAA and other examples of sweeping legislation intended to oversee and control complex social, political, and economic aspects of human life.

The concept of privacy has been reviewed by social scientists and psychologists as both a social issue and a behavioral construct. Margulis (2003) examined various constructs associated with privacy in terms of the benefits of obtaining or maintaining it and the costs of failing to obtain it or losing it. The psychological benefits of personal privacy are that it protects personal autonomy, and that it supports stable relationships with others and personal development because it provides "opportunities to relax, to be one's self, to emotionally vent, to escape from the stresses of daily life, to manage bodily and sexual functions, and to cope with loss, shock, and sorrow" (Margulis, p. 246). It follows that the cost of failing to obtain personal privacy is the loss of these opportunities. The primary cost of losing privacy is the experience of being invaded or violated. Therefore, the Privacy Rule requires that individuals be informed of those persons authorized to access their protected health information and the persons to whom the information will be disclosed. The Privacy Rule also requires that individuals be told

when, if ever, researchers will no longer be authorized to use their protected health information (Shalowitz & Wendler, 2006).

According to Margulis (2003), the social dimensions of privacy are both psychological and political. Socially, privacy is important because people share an interest in it and they also share a belief in their basic right to privacy. Although the right to privacy is not guaranteed in the U.S. Constitution, it is traditionally associated with democratic political systems. Finally, in an increasingly technological world, it is becoming "increasingly difficult for any one person to have privacy unless everyone has a similar minimum level of privacy" (Regan, as cited in Margulis, p. 249). As a result, some people who need patient information and have a right to it are not receiving it (Wilson, 2006).

Some areas of controversy in which privacy is a central social issue are related to the HIPAA legislation conceptually, such as "the government's role as a threat to defender of privacy, consumer privacy, medical and genetic privacy, and workplace privacy" (Margulis, 2003, p. 250). Views of the government as both "threat to and defender of privacy" are often at the heart of discussions of the HIPAA legislation. The privacy of consumer and medical and genetic information, especially, are of particular concern.

In the area of collecting and sharing consumer information, the *opt-in* and *opt-out* concepts, for example, may appear to be simple concepts to information management professionals, but they have been confusing to consumers. In the *opt-out* approach, commercial and institutional entities are permitted to use consumer information unless the consumer objects to their using it. In the *opt-in* approach, entities require explicit

consent or permission from consumers to use their information. Margulis (2003) observed that the opt-out approach is favored by most businesses and commercial entities, while consumers favor the opt-in approach because it gives individuals control over information about them. A crucial example lies in the interpretation of the HIPAA regulations in some hospitals, where patients' names do not appear in the hospital directory unless patients have opted in to being listed there—an often frustrating circumstance for friends and family members who are seeking information about patients. The consequence of the confusion is that many healthcare providers are unsure as to with whom they can now share information, and many clinical researchers are searching for ways to continue research that has been hampered by the Privacy Rule requirements (Wilson, 2006).

Informational privacy was the subject of an exploration of medical and genetic privacy by Alpert (2003). In her view, the crucial aspect of informational privacy for individual consumers is the sources of information about an individual other than the individual, how many there are, and who they are. By inference, the concern in informational privacy is with the degree of control over those sources an individual can exert.

N. P. Terry (2003) observed that the traditional concept of patient privacy was not particularly compatible with the current technological healthcare information environment. In addition to privacy and confidentiality, he considered that the domain of health information has other important properties that must be accounted for, including anonymity, access, what he called *unity* (by which he meant *comprehensiveness*), security, integrity, and quality. In N. P. Terry's view, there are several broad models of health

privacy, distinguished by their primary emphasis, although they are not mutually exclusive, termed *representation-centric*, *collection-centric*, and *disclosure-centric*. The earliest model to emerge, the representative-centric model, emphasizes the presence and expression of a healthcare provider's privacy policy. Its major strength is that providers can be held to account for enforcing or adhering to their own privacy policies. Its major weakness is that if the wording of a privacy policy is at all ambiguous, and most policies are ambiguously worded, there is a great potential for violations of policy. The collection-centric model uses privacy policy to limit the data that can be collected, the conditions under which it can be collected, and the individuals who are authorized to collect it. The disclosure-centric model operates according to confidentiality, rather than privacy policies, and emphasizes what may be disclosed, by whom, to whom, and in what circumstances. N. P. Terry characterized the model in the United States as "purely disclosure-centric . . . based on a strict compliance model" (p. 227).

N. P. Terry (2003) further provided an overview of the various enforcement of process models that overlap with health information protection models and appear to offer some protection to patients' rights. In some cases, patients may have the right to take action based on a warranty; legislative provision for a private remedy for a breach; criminal sanctions for unauthorized collection or disclosure; oversight of data collectors by regulatory compliance processes; and the power to investigate, enforce regulations, or seek remedies invested in a government entity or a "Privacy Officer."

Harrison and Booth (2003) are among the few in the field of informatics who have approached the technological issues associated with personal identity and its associated privacy and confidentiality issues from a conceptual perspective by

concentrating on what they called *digital identity*. In contrast to the models proposed by N. P. Terry (2003), their model is clearly *patient-centric*. In their view, designing technological systems such as the electronic health record on the assumption that an individual's identity is a unique set of data about the individual that can be used for a variety of purposes that constitute looking at the challenge backwards, or upside down. In practical terms, they contended individuals can have multiple identities, one for each "relationship" the individual has with another—such as one or several "health identities" by which one's healthcare provider knows the individual, an identity for citizenship to be used for obtaining or renewing a passport, a taxpayer identity, and a private identity for use with friends, among many other possible identities.

Harrison and Booth's (2003) argument with the use of the word *identity* was essentially that it is usually defined as a unique fixed "set of facts about, or attributes of, the individual" (p. 224). In fact, they contended, this is not the way *identity* functions in reality, where, depending on the context, only specific attributes are considered to establish an individual's identity. A voter, for example, need only establish residency, age, and citizenship; an ATM user needs only a PIN number. In the case of an individual's medical identity, there may be many attributes more important to healthcare providers than an individual's name, such as the individual's age and the history of particular disease treatments.

Further, Harrison and Booth (2003) stated that there are a number of traditional roles and relationships in which personal information about an individual is shared without the explicit consent of the individual. They cited the example of parents who have the right to access their children's school reports, and that of one physician

discussing a patient's case with another physician. In Harrison and Booth's view, access rights are conveyed by a combination of the *role* of a third party and the *relationship* between the third party and the individual. As they described the combination and interaction between role and relationship:

> Role can be regarded as the pre-qualification for, and relationship as the determinant of, access: an individual might well say that they not only want access to their records to be limited to those with medical qualifications, but . . . to be limited to those who also have a relationship with them, such as doctor-patient, nurse-patient, and so on. (p. 225)

The solution to the problem of digital identity for Harrison and Booth (2003) was their proposal of an information technology infrastructure model, Virtual Home®, which uses their concept of roles and relationships to determine who can access personal health information. As an example of the way such an infrastructure could work, the authors used the example of an individual obtaining repeat medication by mail, but not by the already-established electronic transmission of prescriptions from physician-to-pharmacy or pharmacy-to-pharmacy. Instead, they suggested, the individual would give a physician an electronic key that permits write-only access, by which the physician could enter the individual's Virtual Home® and write a prescription there, and also give a pharmacist a different key that permits read-only access to the prescription and requires the pharmacist's electronic signature.

In this example, although the individual gives (electronic) permission to both the physician and the pharmacist, the authors suggested that the permission alone is not sufficient to guarantee the privacy of the information. The granting of electronic keys is an acknowledgment of the *relationships* of the physician and the pharmacist with regard to the individual patient, but not their *roles*, which can also be limited electronically. For

example, an individual cannot get a prescription in virtual or actual reality without seeking it from a licensed physician, nor can an individual have the prescription filled by other than a licensed pharmacist, both of which roles can be specified in the electronic record. The individual controls what information is available to both the physician and the pharmacist and also controls the sharing of the information with others, such as health plan administrators, government or employer benefit programs, and health insurance.

Harrison and Booth (2003) also described how the Virtual Home® model applied to other situations, such as authorizing the state motor vehicle department to share information about an individual's car registration with a village authority in order to obtain a parking permit, or linking bank accounts for information-sharing purposes. They even suggested a possible model for how such a system might be governed and organized, either by a governmental, commercial, or not-for-profit entity. This is a far-reaching, but not necessarily futuristic, idea, the appeal of which is that personal information remains within the control of individuals by their exercise of giving consent or permission for others to access their Virtual Homes® yet takes full advantage of the capabilities of electronic data storage and transmission systems.

Deshefy-Longhi et al. (2004) are among the many who have written of the difference between privacy and confidentiality in the context of the sharing of healthcare information. They cited Farley's argument that the right to privacy is fundamentally based on human dignity and inherent respect for individual autonomy, or the right of individuals to make their own decisions. Defining privacy, however, has not proven to be an uncomplicated exercise for healthcare providers or the courts, although for Westin, the

definition is simple: “the claim of an individual to determine what information about himself or herself should be known to others” (2003, p. 431).

By firmly linking *privacy* and *information*, and locating the development of privacy concerns in the context of technologies and their applications, Westin (2003) declared his position in favor of both protections for personal privacy and a balanced approach to such protections. Westin’s major contribution to the literature in this area was his historical overview of the social, political, technological, and economic developments since 1945 that have contributed to the current position of privacy, which he characterized as “a first-level social and political issue in the United States” (p. 441). In his view, five major technological developments are at the heart of the current position: the Internet, wireless communications, the Human Genome Project, data-mining software, and the government’s blocking of encryption tools that could interfere with governmental surveillance of terrorists and criminals.

Beginning in 1995, Westin and the polling organization Louis Harris and Associates conducted a series of surveys to determine attitudes toward consumer privacy issues. In the first of these phases, they were able to identify three segments of consumers in relation to their degree of concern about privacy: the privacy fundamentalists, who comprised about a quarter of the sample and advocated legislative protections; the privacy-unconcerned, who comprised about 20% and were willing to supply personal information to businesses and the government; and the privacy pragmatists, at 55%, who wanted to know the risks and benefits of supplying information to commercial and governmental entities before deciding to trust them.

By 1999, the end of the second polling phase, the rise of the Internet appeared to be fueling consumers' privacy concerns, although the consumer segments identified in 1995 remained about the same, with the fundamentalists at 25%, pragmatists at 53%, and the unconcerned at 22%. In the next phase—2000–2002—however, the pollsters observed a dramatic shift in public attitude: privacy fundamentalists now comprised 34% of the sample and the unconcerned only about 8%. Westin (2003) attributed this shift in the public's attitudes about privacy to three major developments: 1998–1999 Congressional approval of the mergers in financial services sector, the enactment of HIPAA in 1996, and growing fears of Internet security.

In the context of healthcare, *confidentiality* refers to "restrictions on the ready access to a person's health care information," according to Deshefy-Longhi et al. (2004, p. 380). They cited Beauchamp and Childress, who argued that "confidentiality is a type of informational privacy in that it prevents redisclosure of information previously shared within a confidential relationship" (p. 380), and have distinguished between privacy and confidentiality in terms of the ways in which these two rights are violated: "Privacy is violated when an unauthorized person gains access to another person's private information, whereas confidentiality is violated when someone discloses private information about a person to another person without the first person's consent" (p. 380).

Autonomy is linked to personal identity in fundamental ways, and when an institution honors an individual's autonomy, it is showing respect for an individual's "ability and need for control over his or her thoughts and actions, and over what remains secret and what is shared, and with whom, in order to maintain" the individual's identity (Deshefy-Longhi, 2004, p. 381). C. Jones (2003) indicated that trust in the confidentiality

of medical information enhances patients' autonomy because it gives them a sense of control over their personal information "as a form of property right" (p. 348), in the sense that the medical information "belongs" to the patient. Alpert (2003) observed that when individuals lack control over information about them, when they lack informational privacy or believe that it has been violated, their autonomy is affected:

> If we cannot have some say in how we are perceived by strangers or friends by limiting the disclosure and dissemination of our personal information, we have lost a great measure of our ability to make meaningful decisions for ourselves. (p. 303)

At the heart of most discussions of the privacy of medical information is the concept of trust as it is interpreted by patients seeking medical treatment. As Alpert (2003), among many others, pointed out, the reason that individuals are willing to disclose personal information is that they expect to receive appropriate medical care and treatment based on the information they disclose. The possibility of disclosure, however, makes patients vulnerable to those in whom they confide, diminishing their sense of autonomy. As patients become aware that their private medical information can be accessed without their knowledge or permission, the trust implicit in the helping relationship could erode (Kuczynski & Gibbs-Wahlberg, 2005). Confidentiality in this situation is essential because it

> Not only promotes the free exchange of information between patients and providers, but also protects patients by assuring them that their vulnerability will not be exploited or that the intimate details of their personal life will not otherwise be exposed outside the context of the provider-patient relationship. (Naser & Alpert, as cited in Alpert, 2003, p. 305)

Trust, in the context of the doctor-patient relationship, has also been viewed as "a public good" in the sense that it is a form of social capital, and a limited medical resource,

according to Illingworth (2002). Traditionally, the quality of trust in the doctor-patient relationship has been based on the idea that patients have no choice but to trust their physicians as professionals whose role it is to be trustworthy, because patients want the benefits of what professionals know about and what they are able to do to treat illness. Illingworth disagreed, contending that patients are better informed consumers of healthcare services than they once were, and are more active in letting healthcare professionals and health insurers know what they expect in matters of their health. In fact, Illingworth commented, healthcare services consumers expect physicians and other professionals to behave in ways that communicate their trustworthiness.

However, trust in the doctor-patient relationship works in both directions: physicians must be able to trust that patients will fully disclose all of the information the professionals need in order to make an appropriate diagnosis and recommend appropriate treatment. For this reason, it is in the best interests of both doctors and patients that confidentiality and security of personal medical information are protected as much as possible. As a result, healthcare providers have policies to explain how patient information is used during treatment, payment, or other healthcare operations, as well as procedures for obtaining from the patient a written acknowledgment of receiving the healthcare provider's privacy practice notice (Shoaf, 2003).

In an editorial appearing in the journal *Pediatrics*, Chesney (2001) stated that the federal privacy legislation issued in 2000 contained "confusing, contradictory, and even unenforceable aspects" (p. 1424), commenting that "it seems patently absurd that oral communication of patient information can be policed, especially in a teaching situation" (p. 1424). He was most concerned that the regulations would serve to "eliminate health

services and epidemiological research in some academic entities who do not wish to bear the expenses of potential civil liabilities" (p. 1424). Although this position suggested the worst case scenario, the public may not want to stifle this research. Hence, the law of unintended consequences may hold.

In another editorial, this one published in the *American Journal of Critical Care*, Dracup and Bryan-Brown (2004) also invoked the law of unintended consequences, suggesting that it "may have landed squarely in the healthcare arena in the form of the Health Insurance Portability and Accountability Act of 1996" (p. 97). In their view, the framers of the legislation had good intentions, but "underestimated the frequency and intensity of information exchange in healthcare" (p. 97). Harman (2005) stated that in an electronic environment, protecting privacy has become extremely difficult, and patients are becoming increasingly concerned about the loss of privacy and the inability to control dissemination of information about them. As patients become more aware of the misuses of information, they may become reluctant to share information with their healthcare providers.

Interestingly, and perhaps typically, Dracup, a registered nurse, and Bryan-Brown, a physician, discussed the various impacts of HIPAA at the bedside, in healthcare facilities, and on research, leaving out on the consumer. They were particularly concerned about implementing HIPAA regulations in intensive care units, where the demand for information about patients is great, and not only by family members. In their view, the regulations constitute a major setback to recent efforts to make staff and intensive care units more accessible to families. In healthcare facilities, Dracup and

Bryan-Brown's main concerns are with the cost of reconfiguring the intensive care environment to assure privacy and confidentiality of patients and information about them.

The field of medical informatics has not ignored the concept of trust in the doctor-patient relationship, because a number of principles are at work that directly affect the use of electronic health records. As Fairweather and Rogerson (2001) pointed out, the rapid development of information management systems and their application to the field of healthcare has outpaced the ability to think carefully about the ethical aspects of their use. In their view, the essential principles of medical ethics are *beneficence* (act in the best interests of patients), *nonmaleficence* (do no harm), and respect for patients' autonomy (their ability to make their own decisions).

In considering the ethical aspects of the electronic medical record, Fairweather and Rogerson (2001) observed that the use of that record may conflict with the principles of medical ethics, citing the example of the activities of medical information clearinghouses in the United States that sell patient information to a wide range of customers, including employers, pharmaceutical companies, law enforcement agencies, and insurers. Others have commented these authors also found that patients' awareness that information about them can be widely circulated may inhibit them from telling healthcare professionals about their symptoms and their health.

From the viewpoint of medical informatics, Fairweather and Rogerson (2001) chose the controversial issues: consent, access, privacy, and confidentiality. In their view, there is no such situation as complete privacy, nor is complete lack of privacy possible; the concept is relative when applied to the electronic medical record. They suggested that, at least in principle, each piece of information about an individual could have a different

privacy "rating" that could be determined by the number of others—individuals or organizations—permitted access to that item of information. Theoretically, the range is from complete privacy, a state in which no one but the individual knows a particular piece of information about the individual, to zero privacy, a state in which everyone knows a particular piece of information about an individual.

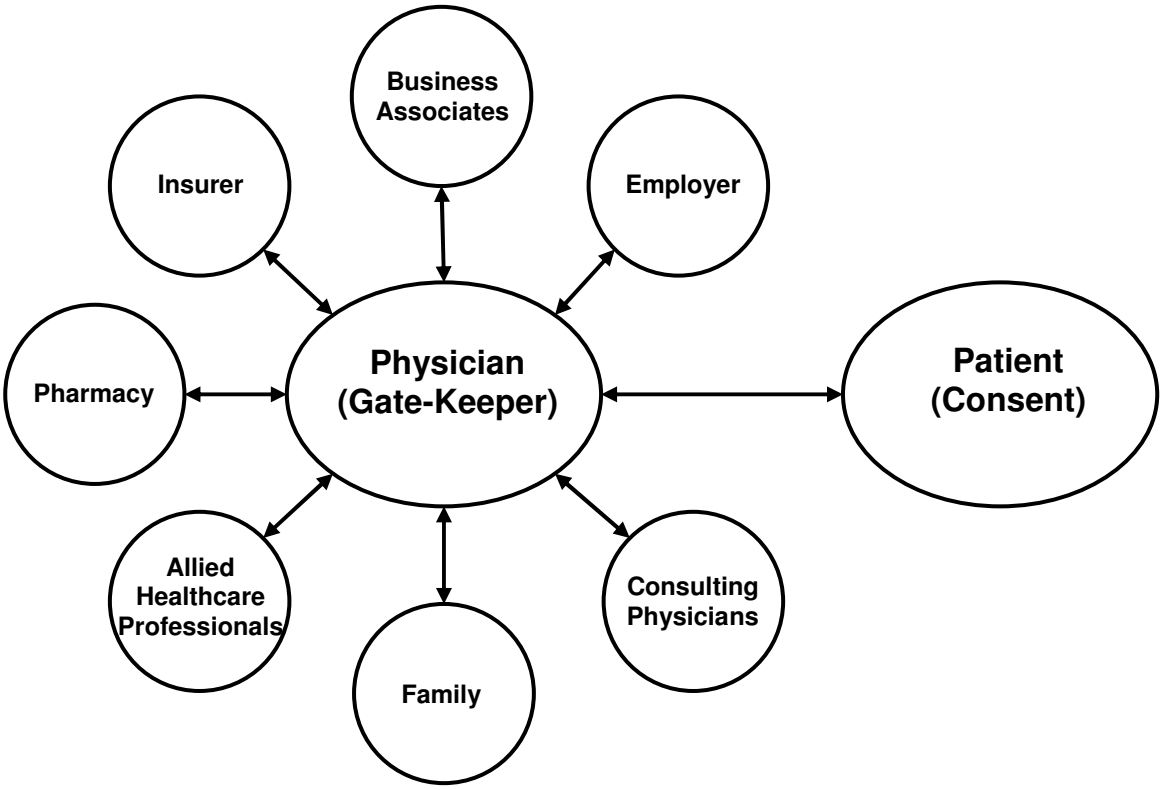

Figure 1. HIPAA framework.

The physician is the central hub and processing center of the patient's records. After initial consent is given by the patient, the physician's role as "gate-keeper" is to ensure the responsible exchange of protected health information to those participating in the patient's care.

Privacy and the Effects of HIPAA Legislation

Scott (2003) suggested that the objectives of Congress in passing the HIPAA regulations were to

1. Improve the quality, efficiency and effectiveness of the nation's health delivery system.
2. Encourage the development of a health information system through the establishment of standards and requirements to enable the electronic exchange of certain health information.
3. Expose fraud and abuse.
4. Protect Privacy and Confidentiality.
5. Emphasize the Private Sector.
6. Hold down costs. (p. 1)

The act requires healthcare providers and organizations, including hospitals and insurance companies, to follow external government regulations. To make this possible, HIPAA requires interpretation and enforcement. Therefore, the implementation of these regulations affects organizations' strategic management plans. The HIPAA legislation is national in scope, sweeping in its coverage, and far-reaching in its implications, and thus covers a wide range of stakeholders. As a result, there are perceived disadvantages of the HIPAA law from the healthcare providers' perspective as it relates to the consumer. In fact, Nicholas and Blumberg (1998) stated that the evolution of perceptions about HIPAA's effect and enforcement may be as important to future policy decisions as its objective and measurable effects are. Influences about HIPAA's successes and failures are likely to shape healthcare reform discussions in the United States for some time to come.

There have been several overlapping and contradictory legislative actions in the last several years, some of which were addressed when HIPAA legislation was enacted. As Parker (2003) stated, the privacy provisions in the original Health Insurance

Portability and Accountability Act began as a 337-word guideline, but the final regulations swelled to 101,000 words. The regulations were issued at the end of the Clinton administration but revised by the Bush administration. For example, doctors and other healthcare providers are required to furnish written notice to patients describing the regulations and patients' rights.

From the perspective of the consumer, polls have indicated that the public is very concerned about the lack of privacy of medical information. Lack of confidence in the security of health information leads patients to be untruthful or withhold information from healthcare providers, or sometimes avoid care altogether (Pollio, 2005). Pollio further stated that these types of behaviors can compromise both individual and public health initiatives.

The OCR (2003) stated that the Privacy Rule addresses standards for the use and disclosure of individuals' health information or "protected health information" by organizations subject to the Privacy Rule or "covered entities," as well as standards for individuals' privacy rights to understand and control how their health information is used. Within the U.S. Department of Health and Human Services, the OCR has responsibility for implementing and enforcing the Privacy Rule with respect to voluntary compliance activities and civil money penalties.

Just as there has been much written about HIPAA in the public sector, it has also received considerable attention in the private sector. Professional and scholarly literature suggest that the effect on the consumer of healthcare services should be widespread. In addition, it is strongly suggested that the full extent of the effect will not be known for some time. Providers must make difficult decisions about when, how, and to whom to

disclose health information in accordance with the Privacy Rule's complicated restrictions (Kulynych & Korn, 2003). Since the legislation has so recently been implemented, there has not yet been time to document the specific effects on specific consumers; however, the literature shows several clear directions the effects will most likely take in the near future. For example, Dunea (2004) indicated that unfortunately the Rule is now having distressing consequences. These seem to arise largely from uncertainties in understanding its complicated provisions, misinterpretations, and anxiety about breaking the law and incurring heavy penalties.

In clinical practice, a common side effect of the Privacy Rule is that physicians and their staff sometimes do not know when and to whom they can legally distribute patient information (Wilson, 2006). According to Wilson, violating HIPAA's administrative requirements could result in civil penalties from $100 to $25,000 for repeat violations and up to 10 years' imprisonment. Wilson further stated that, as a result, some people who need patient information and have a right to it are not receiving it. This is most probably due to misperceptions regarding the Privacy Rule on the part of the healthcare provider.

It is expected by some that the overall effect will be on the quality of healthcare that consumers receive. More specifically, there are indications that there will be effects on public health reporting, much of which is already mandated by federal or state legislation. Confusion over the required reporting of birth and death statistics, incidence of specific diseases and conditions, and similar information that has been traditionally seen as the province of public health may seriously impair the collection and dissemination of vital information that affects the health of large numbers of the general

public. A third area of concern is the potential effects of the HIPAA legislation on the entire process of medical research. While established research traditions have been thought to protect patient confidentiality and privacy, the recent implementation of the HIPAA legislation has been something of a shock to the research community, which is presently scrambling to reevaluate processes that have been in place for years.

It has long been a complaint with the healthcare industry that archaic information systems of U.S. hospitals and clinics directly affect the quality of care patients receive. When a patient visits a new hospital or clinic, it most likely will have little information about the patient and no way to track how other providers have treated the patient in the past (Swartz, 2004).

This is one of the essential arguments in favor of the electronic health record. However, Bowers (2001) stated that healthcare providers believe that the privacy rules will impede their ability to treat patients. This is due to the complexity of the rules, which makes complying difficult. Still other healthcare providers regard the HIPAA regulations as a bureaucratic impediment to patient care rather than an advance in protecting confidentiality (Lo et al., 2005).

Swartz (2004) cited the *Journal of the American Medical Association* report showing that as many as 98,000 patients die each year in U.S. hospitals "from preventable medical errors, such as receiving the wrong medication. Nearly half of all patients do not get all the treatment or tests that they should have received" (p. 20). Medical errors have also been linked to

> Multiple physicians treating the same patient without all having access to all the patient's medical records and with each storing different, incomplete medical records in different places. There is near consensus among healthcare industry

> experts that the widespread use of electronic health records, accessible to all those seeing and treating a patient as well as to the patient, would substantially improve the coordination and quality of health care. In addition, electronic prescribing would further reduce errors that result from handwritten, hard-to-decipher prescriptions. (Swartz, pp. 20–21)

Another area of the healthcare industry from which concern has been expressed about the HIPAA regulations is that of public health reporting. Public health reports, many of which are already mandated by federal and state legislation, cover information about surveillance of cases and outbreaks of certain diseases, complications of birth, causes of death, and similar bodies of knowledge that help inform public health policy and healthcare services. Generally, public health agencies are exempted from HIPAA regulations because they are considered lawful recipients of personal health information. These agencies include public health entities on the local, tribal, territorial, and state levels, and federal agencies such as the Centers for Disease Control and Prevention, the Food and Drug Administration, the National Institutes of Health, and the Substance Abuse and Mental Health Services Administration, among others (Campos-Outcalt, 2004).

Despite the exemption of public health agencies from the HIPAA privacy regulations, the regulations are still considered to have a potential effect on public health practices because of the likelihood that nonpublic organizations will misunderstand the need for authorizations and consents with regard to their disclosures of vital public health information. In particular, there is great concern over the so-called “hybrid” health entities, such as public health agencies that provide healthcare services to the disadvantaged or those that operate in partnership with hospitals, physicians groups, and community clinics. In these cases, the legislation mandates that public health agencies

adhere to the HIPAA regulations in the areas where they provide treatment, payment, and healthcare operations. Some writers have predicted a faltering of public health reporting in the wake of the implementation of the HIPAA regulations (Kutkat, Hodge, Thomas, & Bonta, 2003).

Concerns about the potential effect of the HIPAA regulations on the conduct of medical research are apparent in publications and professional journals. Holt (2003), for example, examined the effects of the regulations on the work of Institutional Review Boards (IRBs), those bodies responsible for protecting the rights of patients participating in research studies, which includes their right to privacy, and for minimizing the risks to patients of their participation, including the risk of disclosure of protected health information. To highlight the regulatory effects of HIPAA on the research process, Holt focused on the difference between the already well-established *informed consent* required of participants in the research studies and the *authorization* required by the HIPAA regulations. The HIPAA authorization is essentially pro forma permission to use patient information for the purpose of research, while the informed consent is the patient's consent to participate in a study; but the distinction goes much farther than that.

The HIPAA authorization form is extremely detailed in terms of its requirements, which include a description of the information that will be used, who will use it and/or who will disclose the information, to whom information will be disclosed, the purpose for which information will be disclosed, a date on which the authorization will expire, and the patient's signature and date of signature. One exception to the requirement of authorization may seem routine to medical professionals, but it will serve to highlight the kinds of loopholes even this particularly complex legislation presents from the patient's

point of view. Therefore, HIPAA appears to inhibit medical record and database research (O'Herrin, Fost, & Kudsk, 2004). Bolcic-Jankovic (2007) further stated that the purpose of HIPAA was to inform and educate patients about privacy rights. According to the Rule, medical researchers, regardless of source of funding, are required to obtain an authorization from patients to gain access to protected health information for research purposes. The requirement to obtain permission can have a substantial effect on the conduct of research.

Under HIPAA regulations, authorization is not required for the disclosure of patient information to nongovernmental entities under the jurisdiction of the Food and Drug Administration (FDA)—that is, pharmaceutical manufacturers and their representatives. The rationale for this exemption is that disclosure of certain types of information to FDA-regulated entities—such as drug-related adverse events, information needed to track and recall pharmaceutical products, and information needed to conduct safety surveillance—is already mandated by legislation. Much of the confusion over implementing HIPAA regulations with healthcare organizations and their business associates arises out of the overlapping of different sets of federal regulations.

The effects of participation in clinical research under HIPAA regulations are not yet known, but Holt (2003) suggested some possibilities. For example, by giving consent to participate in research studies involving medical treatment, patients agree that they will be denied access to their own health information during the period of the research. In addition, researchers may find that the regulations make even recruiting research participants more difficult, since recruitment is considered "research" and therefore subject to the various restrictions in the HIPAA regulations.

In the view of Kouzoukas (2002), the HIPAA regulations deal with research on a nearly philosophical level, acknowledging that there is an inherent tension between the protection of private information and the essential aim of medical research, the search for "generalized knowledge" (p. 13) that can be used to improve health care. Kouzoukas commented that while the regulations are intended to protect personal medical information, a laudable purpose, they are effectively imposing restrictions on the process that is at the heart of the healthcare industry, the contribution that research makes "to increasing the quality and length of human life" (p. 14). Kouzoukas concluded that the regulation "addresses the tension between privacy and the value of knowledge in classic regulatory fashion: by sidestepping the question, leaving it to regulated entities (IRBs and patients) to answer on a case-by-case basis" (p. 19).

Durham (2002) is among the few researchers to see some positive effects of the HIPAA regulations on the research community. For example, she cited the need for researchers and their sponsoring organizations to be more careful to develop policies and practices for sharing personal medical information. In general, researchers need to enhance their technological capabilities as well, in order to ensure that they "de-identify" medical information in order to protect the privacy of individual research participants. Further, Durham considered the most far-reaching potential effects of the legislation to be "the enhanced trust of the American public" (p. 492), a quality that she, along with others, sees as having been seriously waning in recent years.

In an editorial, Dracup and Bryan-Brown (2004) contended that while "no evidence exists that research jeopardizes confidentiality of patient information" (p. 99) and research itself is not covered under the HIPAA regulations, the regulations have cast

a shadow over the research process in many instances, primarily because of concerns about protecting the elements of personal health information that can identify patients. The requirement that patients sign a form saying that their information may not remain confidential if they participate in a study may discourage some from participation in research studies.

In their discussion of protections afforded the subjects of genetic research, S. F. Terry and Terry (2001) dealt with a series of what they called "myths" (p. 259) that exist in the genetic research community. The first myth they tackled was that "privacy is possible." Their viewpoint was that privacy is impossible in an age of "electronic records, pervasive data gathering, and behavior surveillance" (p. 259). Of more concern is the misuse of information. Particularly in genetic research, research subjects and information about them cannot be protected by de-identifying the information, because the subject of the research is DNA, and DNA "is the ultimate identifier" (p. 259).

The foregoing discussion takes in the wider concerns in the healthcare industry about HIPAA legislation, concerns that may take some time to trickle down to individual consumers. There is a growing body of literature that assessed the potential impact of the HIPAA legislation on individuals, which suggests that it may affect consumers' confidence in the overall healthcare system in the country, their belief and trust in the traditional doctor-patient relationship, and their confidence in the technological advances that have recently transformed medical record keeping. Patients must also be educated about their privacy rights so that they do not inadvertently sign them away or allow them to be unnecessarily suspended. Patients should be aware that exceptions to HIPAA rules

permit healthcare providers to give medical records to the government without prior patient authorization for "national security" reasons (Kumekawa, 2005).

"When professionals keep patients' information private, they promote effective medical treatment by establishing trust in the patient-provider relationship" (Deshefy-Longhi et al., 2004, p. 381). This statement essentially sums up the perspective of consumers with regard to the relationship between privacy and trust.

Hussong (2000) stated that the doctor-patient relationship may be compromised by widespread access to medical records because patients will be reluctant to share sensitive information with their healthcare providers. Physicians have expressed the fear that patients will not seek treatment because the patients are concerned that their conditions, such as substance abuse, mental illness, genetic disorders, alcoholism, and other similar conditions, will be disclosed to parties with whom the patients do not wish to share their protected health information.

C. Jones (2003) presented the utilitarian argument, which guarantees confidentiality of personal medical information: "failure to guarantee confidentiality will lead to non-presentation, misdiagnosis, or failure of treatment, and ultimately cause more harm than maintaining confidentiality" (p. 348). In a pilot study, C. Jones found that patients would appreciate discussing confidentiality limits with their physicians, even though they recognized that this might deter them from seeking treatment. They appeared to believe that the potential risk to a third party outweighed an absolute standard of confidentiality. There was also a gap between what patients in this study thought their physicians should do and what they believed they actually do.

In a review conducted by Sankar, Moran, Merz, and Jones (2003), their findings suggested that concerns about confidentiality influenced patients' willingness to disclose personal information to physicians. Among the patients for whom this is a problem, HIV-positive patients were found to withhold their diagnosis from doctors because they did not trust them or the healthcare setting to keep the information confidential (Kochen, Hasford, Jager, et al., 1991; Madge, Jones, Mocroft, et al., 1999; Marks, Mason, & Simoni, 1995; Moneyham, Seals Demi, et al., 1996; Petchey, Farmsworth, & Williams, 2000; among others, as cited in Sankar et al., 2003).

There is also a growing body of literature that considers the effect of HIPAA legislation on special groups of consumers, including adolescents and patients in mental health and substance abuse programs. A great deal has also been written about the privacy of genetic information, a subject that is beyond the scope of this review and the current research. As Deshefy-Longhi et al. (2004), among others, observed, certain groups of patients are particularly vulnerable to breaches of privacy and the confidentiality of their medical information because of their age (very young or very old), their minority or immigration status, and their particular medical conditions, including sexually transmitted diseases (STDs), HIV/AIDS, mental illness, and terminal illness.

Chesney (2001) is among those who pointed out those individuals with rare diseases are often listed in registries supported by foundations and nonprofit organizations, and even major healthcare organizations. Chesney was eloquent in expressing the concerns of investigators with regard to these special populations:

> As new therapies become available, can these patients be contacted? Does the public wish to shut down these registries? Authorization is needed to release information to nongovernmental registries. However, once the registry has the

> information, it can be used in ways the registry wishes because these registries are not covered entities [under the legislation]. (p. 1425)

Chesney (2001) also questioned the regulations as they existed in 2000 with regard to protecting the confidentiality of adolescents. He was particularly concerned about the processes that healthcare organizations would adopt in order to distinguish between health information that minors "own" in terms of privacy rights and information that must or should be disclosed to their parents.

After those concerned with confidentiality in HIV testing, the most studies about the influence of confidentiality attitudes on the decision to seek treatment were studies of adolescent subjects. When adolescents are asked why they do not seek healthcare, they frequently report a lack of trust in the intent of private physicians to withhold information from their parents (Sankar et al., 2003). The comprehensive review conducted by Sankar et al. also showed that adolescents tend to withhold information from healthcare providers because they are concerned about the confidentiality of that information.

In Maradiegue's (2002) view, adolescent patients are likely to suffer under the HIPAA regulations, in keeping with a history of difficulties associated with implementing health regulations in this vulnerable population. Maradiegue is one of the few clinical observers to acknowledge that the HIPAA regulations were developed and are being implemented in a particularly difficult political climate. The federal regulations are highly complicated with regard to where they converge with state laws, and nowhere is the intersection more politically laden than in areas of confidentiality and control of personal medical information that affect adolescents.

As Maradiegue (2002) described, the relevant political climate—the conservative right, a major influence in the current administration and Congress—is well known for its opposition to adolescents' access to family planning, abortion, and related services without parental notification and consent. In some states, however, the access of adolescents to mental health, substance abuse, and family planning services is not restricted by requirements of parental consent and notification. This conflict is evident in the U.S. Congress, which has attempted, unsuccessfully, to pass more restrictive legislation (National Center for Public Policy Research, as cited in Maradiegue).

Confidentiality is apparently of primary importance to adolescents seeking healthcare services related to family planning, STDs, substance abuse, and mental health, all of which are extremely sensitive areas. The issue related to the HIPAA regulations is how much privacy will be accorded to adolescent patients and their personal medical information, and how confidentiality requirements will be interpreted with regard to their parents' access to medical record information. This issue has not yet been resolved, and, in the view of Maradiegue (2002) and others, not likely to be for some time unless healthcare researchers are able to support public policy making in the area of adolescent health.

In analyzing the effect of HIPAA legislation on adolescents and their access to confidential healthcare services, English and Ford (2004) found that the state in which an adolescent resides and the site where he or she seeks healthcare are the two factors that will determine how the HIPAA regulations are applied. While adolescents are able to give their consent to screening for sexually transmitted diseases and for family planning services in every state, only in some states are their parents able to access information

about these services. Difficulties also arise in private physicians' offices around billing and third-party reimbursement practices, particularly for adolescent patients covered under their parents' health insurance plans. In school-based health clinics, many of which offer family planning services and STD screening, parental consent is required, although in some cases it may be a blanket or general consent for treatment. There is some overlap on federal regulations about disclosure of information in schools, which has caused confusion about what may and may not be disclosed to parents seeking health information about their adolescent children. English and Ford viewed state laws as highly vulnerable to the current federal atmosphere of support of parental control over all aspects of children's lives, including the independent healthcare decisions made by adolescents.

Another vulnerable group of healthcare services patients are those seeking or receiving treatment for substance abuse and mental health problems. Mental health professionals in particular have expressed concern about the potential effect of the HIPAA legislation, primarily in editorials and opinion pieces. Among the few studies to address this area of concern was that conducted by Lorence (2004), in a national survey of medical information managers regarding measures adopted in mental health services settings to ensure the confidentiality and privacy of personal medical information.

Lorence (2004) found that the information management professionals he surveyed did not universally require signed confidentiality statements from healthcare employees with access to electronically collected, stored, and transmitted information, even in those organizations that had adopted advanced computerization of medical records. He concluded that "technology itself does not always effect a . . . change in organizational

practices, especially where they are ingrained in a long-standing paper-based culture" (p. 205). To respond to HIPAA, physicians and hospitals need to review operational processes related to location of medical records, access to medical records, access to databases that house protected health information, and disclosures. They need to revise authorization for release of information and create new documents, such as a notice to patients regarding the use of their protected health information (Bowers, 2001).

Kulynych and Korn (2003) suggested that the Privacy Rule creates significant new barriers to the use or disclosure of identifiable health information by imposing an intricate series of organizational and procedural requirements on the entities it covers. They further stated that achieving compliance with the Privacy Rule is not simply a matter of creating new policies, procedures, forms, and notices that the Rule requires. In addition, providers must also make difficult decisions about when, how, and to whom to disclose health information in accordance to the Rule's complicated restrictions.

Confidentiality and Disclosure

There has been little empirical literature published to date that offers insight into patients' views of privacy and confidentiality, although the practitioner literature is full of anecdotal articles and empirical studies of professionals' attempts to assure patient privacy and confidentiality. One of the few empirical attempts to explore these concepts with patients reported the results of focus group discussions, that were held before HIPAA was implemented, with nurses and their patients in the primary care practices staffed by Advanced Practice Registered Nurses throughout southern New England (Deshefy-Longhi et al., 2004).

Deshefy-Longhi et al. (2004) conducted focus groups as the first phase of a multiphase project in order to develop a survey questionnaire that would explore the perspectives of primary care nurses and patients on a wider scale. From the discussions in these focus groups, the researchers were able to identify a range of privacy and confidentiality issues that matter to both patients and practitioners, including breaches through carelessness, concern about over-regulation, establishing trust between patient and provider, the overlap when providers become patients, patient control of their health information, sensitive information (e.g., HIV status), electronic storage or transmission, mandated disclosure, and issues related to the healthcare of adolescents. The last three issues were identified by nurses only, and not by patients; the rest were identified by both groups.

Hussong (2000) noted that patients were also concerned that their private medical information may be used, for example, by prospective employers, that their credit and financial status may be compromised, that insurance companies will use genetic information to deny them coverage, that managed care companies will refuse care to individuals with conditions that require expensive treatment, and that pharmaceutical companies will solicit their business without permission.

C. Jones (2003) conducted a study to develop a questionnaire to discover how important medical confidentiality was to patients, how strong their support of disclosure of confidential information to third parties was, and whether they believed that lack of confidence in the privacy of medical information would affect their willingness to fully confide in their healthcare providers. As C. Jones observed, it is generally assumed that confidentiality is important to patients, yet few researchers have asked them directly. In

addition, C. Jones wanted to test patients' support of an absolute standard of confidentiality by asking about specific situations in which they would support disclosure of personal medical information to a third party. The participants in this pilot study were given five scenarios (involving driving while impaired, mental illness, sexually transmitted disease, child abuse, and intent to kill another) and asked whether they would support a doctor's disclosure of information to a third party in order to prevent harm of another or others.

Although C. Jones (2003) acknowledged that the sample in this study was small (only 20 participants), that the questionnaire used had not been validated, and that the wording of the scenarios was ambiguous in some cases, the views expressed by the participants about confidentiality were highly complex, suggesting that much more empirical work needs to be done on the assumption that patients tend to hold doctors to an absolute standard of confidentiality.

In C. Jones's study, patients were asked some general questions before the scenarios were presented about their expectations of confidentiality and again after they considered the scenarios, to see whether there was a difference in their views. The general questions asked if they think disclosure is ever acceptable without their consent, if there is any subject they would not discuss with their doctor because the doctor may tell someone else, if their doctors have ever discussed confidentiality with them, and if they wanted to be informed of any exceptions to confidentiality before seeking treatment.

Based on this pilot study, C. Jones (2003) suggested that the following hypotheses are worthy of future research:

> Patients generally recognize that breaches of confidentiality may deter patients from seeking further treatment, but nonetheless many patients will support disclosure to protect third parties; patients' expectations about disclosure will vary depending on the nature of the risk involved; patients who are concerned for their own confidentiality will be less likely to support disclosure in hypothetical situations; patients in health care settings where disclosure is potentially particularly damaging will value confidentiality more highly. (p. 352)

Sankar et al. (2003) reviewed the literature for studies regarding patients' views of medical confidentiality. The review, published in the *Journal of General Internal Medicine*, obviously intended for a professional audience, was aimed at increasing their awareness of the wide range of patient attitudes towards confidentiality. Out of more than 5,400 articles, the majority were written from the practitioners' point of view, focused on the need for reforms, confined the discussion to research subjects, or discussed regulations. After excluding editorials and opinion pieces, articles not based on research with patients, and articles describing confidentiality outside of the clinical encounter, 110 studies were grouped into four categories: patient understanding and awareness of confidentiality, limits to access, effect on treatment seeking, and effect on disclosure of personal information to healthcare providers.

Summary

Literature concerned with the impact of the recently implemented HIPAA regulations on consumers is still in its early stages. The final regulations were issued in the spring of 2003, and although healthcare organizations and other stakeholders have known since 1996 that this legislation was pending, it is still too soon to assume that all organizations and associated parties have had time to fully implement the necessary policies and procedures in order to meet the letter and the spirit of the law in this case.

Consumers, meanwhile, continue to experience confusion on a practical level. Some hospitals keep patient registers confidential unless patients opt in to be listed there. Patients spend more time in waiting rooms in doctors' offices reading "privacy notices" that they must sign and presumably understand before they can receive healthcare services. Moreover, they interact with healthcare providers who are themselves often confused about the regulations.

Of the concerns expressed in the professional and scholarly literature, including public health reporting and medical research, there are several that stand out as being potentially important to consumers of healthcare services. While these concerns may seem removed from the actual experience of the consumers of healthcare services, in the long run, disruptions in these processes may have far-reaching impacts on their actual health.

The current experience of consumers of healthcare services is evolving against a background of eroding confidence. In the background is consumers' lack of confidence in the overall healthcare system in the country, brought on by rising costs, the loss of health insurance, reports of medical and pharmaceutical errors, and breaches of confidentiality. In addition, as this review has suggested, there is a coincident loss of confidence in the privacy of the doctor-patient relationship, as managed care steadily limits the amount of time physicians have to spend with their patients, among other factors. Finally, there is some evidence that the technological advances that have made the electronic medical record a reality in many healthcare organizations have outpaced the ability of medical professionals and health policy makers to undertake the careful ethical analysis that is so

necessary to ensuring that technology does not contribute to eroding privacy rather than supporting privacy.

The literature makes clear that some patients are more vulnerable than others to breaches of confidentiality and disclosure of their personal medical information to third parties without their consent. These patients include the very young, the very old, adolescents seeking family planning and other sensitive services, and consumers of mental health and substance abuse services. With parents, employers, insurers, law enforcement, and others seeking medical information, it is no wonder that patients feel under siege. This research focused specifically on the privacy aspect of HIPAA and questioned its effects on healthcare providers and consumers.

CHAPTER 3. METHODOLOGY

This chapter describes the research methodology for the determination of consumers' and primary healthcare providers' perceptions of HIPAA and privacy as it relates to the interpretation and application of the regulations by primary healthcare providers. To accomplish this research, the researcher employed a quantitative methodology using a questionnaire survey instrument. The research identified the perceptions of consumers and physicians regarding HIPAA and privacy related to the consumers' medical information in the application and interpretation of the regulations by primary healthcare providers.

In addition, this research sought to determine if the possible ambiguity of the HIPAA guidelines adversely affects consumers (patients) as a result of the interpretation and implementation of the regulations by primary healthcare providers.

Research Question

Do the perceptions of healthcare providers regarding privacy effect patient care?

Hypothesis

H1o: There is no difference in HIPAA perception between providers and consumers of care.

$H1_A$: There is a difference in HIPAA perception between providers and consumers of care.

To test the hypothesis, the researcher used the questionnaire survey from Slutsman (2004). According to Slutsman, "the study sample consisted of a cross-sectional study which used an original instrument to survey a random sample of 2,000 physicians drawn from the American Medical Association Physician Masterfile" (p. 4). Only those physicians who were actively practicing medicine were included in the study. As indicated by Slutsman, the goals of the study were to provide a reliable baseline on physicians' views and experiences with the Privacy Rule, and provide an early assessment of the expected effects of these provisions on relevant practice outcomes. The study was quantitatively validated. Face validity was established by having the survey reviewed by several outside experts (including a medical sociologist, psychometrician, and an investigator from the American Medical Association. As with the Slutsman survey, this research will involve physicians' perceptions regarding HIPAA and patients' perceptions regarding privacy.

This research identified the perceptions of private practice physicians regarding the possible effect of patient care in relationship to the interpretation and application of the HIPAA rules. The previous research conducted by Slutsman (2004) consisted of 28 questions in various categories that addressed various privacy and confidential protections at the organizational and individual physician levels.

Research Design

The design for this research was a cross-sectional study, with the data being collected at a single point in time. According to Bryman and Bell (2003), a cross-sectional design entails the collection of data on more than one case (usually quite a lot more than one) and at a single point in time in order to collect a body of quantitative or quantitative data in connection with two or more variables (usually many more than two), which are then examined to detect patterns of association. Likewise, Olsen (2004) stated that one of the most common and well-known study designs is the cross-sectional study design. In this type of research study, either the entire population or a subset thereof is selected, and from these individuals, data are collected to help answer research questions of interest.

According to Robson (2002), quantitative designs are usually concerned with aggregates, group properties, and general tendencies. In traditional experiments, results are reported in terms of group averages rather than what individuals have done. For this study, the research employed a questionnaire survey instrument. The research determined consumers' perceptions about the privacy of their personal health information and HIPAA regulations as well as the possible effect of HIPAA as a result of the interpretation and application of regulations by healthcare providers. The researcher developed a matrix in order to illustrate which survey questions addressed and supported the hypothesis (see Table 1).

Table 1. Matrix for Hypothesis

Variable	Instrument questions	
	Physician survey	Consumer survey
Demographics	1, 2, 3, 4, 5, 6, 11	1, 2, 3, 4, 5, 6, 7, 8, 11
Privacy	7, 8, 9, 20, 21	7, 8, 9, 20, 21
Confidentiality/disclosure	12, 13, 14, 15, 16, 17, 18, 19, 22, 23, 26, 27, 28, 29	12, 13, 14, 15, 16, 17, 18, 19, 22, 23, 26, 27, 28, 29
Patient care	10, 24, 25	10, 24, 25

Population and Sample

The target population for this study comprised private practice physicians and their patients who are located in a medical center in Pontiac, Michigan. From this population, the researcher identified samples of consumers and private practice physicians. That is, both urban and suburban patients were surveyed. Likewise, professionals as well as nonprofessionals were surveyed. Collectively, the physicians saw approximately 926 patients per day.

The goal of the research was to examine consumers' and private practice physicians' perceptions with respect to the HIPAA regulations and the possible adverse effects resulting from the interpretation and application of the regulations by healthcare providers. The researcher sought to construct a sample of consumers and private practice physicians.

The sample size for this population was 278, which was determined by using a sample size calculator. The researcher distributed 920 surveys. The formula used in the

sample size calculator to calculate sample size was Z^2 x (p) x (1 - p) ÷ c^2. Z = Z value (e.g., 1.96 for 95% confidence level), p = probability that the population accuracy is represented, expressed as a decimal (.5 used for sample size needed), and c = confidence interval, expressed as decimal (e.g., .04 = ± 4). The Sample Size Calculator is presented as a public service of Creative Research Systems (2003).

According to Bryman and Bell (2003), with random sampling, each unit of the population has an equal probability of inclusion in the sample. Likewise, Robson (2002) suggested that, if properly conducted, random sampling gives each person an equal chance of being included in the sample, and also makes all possible combinations of persons for a particular sample size equally likely. In addition, Leedy and Ormrod (2005) stated, to some extent, the size of an adequate sample depends on how homogeneous or heterogeneous the population is. The researcher expected the population sampled to be homogeneous with respect to their perceptions regarding privacy and HIPAA.

The single-stage (random) sampling procedure was administered directly while the respondents were waiting to be seen by the healthcare professional. According to Bryman and Bell (2003), with random sampling, each unit of the population has an equal probability of inclusion in the sample.

Data Collection

The office managers in each physician's office or clinic administered a self-completion survey questionnaire to each respondent while he or she was waiting to be seen by the physician. The survey was given to nonpregnant consumers age 18 or older of various ethnic, age, gender, educational, and income groups. The researcher expected the

response rate to be at least 30%, because the questionnaire survey was administered in a closed environment. The private practice healthcare providers' survey was hand-delivered to each individual office or clinic and collected by hand upon completion. It was expected that the survey questionnaires would be completed in the offices of the physicians.

Instrumentation

A questionnaire survey consisting of 29 questions was administered to patients and physicians. The survey questions were directed to physicians and patients to determine their perceptions regarding privacy, confidentiality, and disclosure of patient protected health information. Additionally, the survey asked questions relating to patient care and HIPAA. Specifically, 21 of the 29 questions addressed perceptions relating to privacy, confidentiality, disclosure, and patient care pertaining to patient protected health information. The remaining survey questions for the respondents related to demographic parameters, such as age, income, education, gender, marital status, ethnicity, and employment. The researcher developed a matrix in order to illustrate which survey questions addressed and supported the hypothesis (see Table 1). In addition, the researcher developed a matrix to represent and support the research question. The results are in Table 2.

Table 2. Matrix for Research Question

Independent variable	Physicians' perception of privacy	Liberal	Conservative
Dependent variable	Possible effect on consumer care	Positive	Negative
Q10		Strongly Disagree Disagree Unsure	Strongly agree Agree
Q24		Very good Good Fair	Poor Unsure
Q25		Very good Good Fair	Poor Unsure

An invitation to participate in the survey accompanied the questionnaire survey and was distributed by the office manager in each physician's office or clinic. Each patient respondent was given the Consumer/Patient Questionnaire survey to complete or fill in the responses without assistance and with complete anonymity. Likewise, each physician was given the Healthcare Provider Survey to complete or fill in the responses without assistance and with complete anonymity.

The researcher completed a field study of the survey instrument to determine the reliability of the instrument as well as to determine the clarity of the research questions. The field study resulted in recommended changes that were made to the instrument. The participants in the field study consisted of five experts on the subject of HIPAA.

Validity and Reliability

Validity refers to the accuracy of the study, while reliability refers to stability or consistency by which something is measured (Robson, 2002). According to Simon (2002), reliability provides an estimate of how well measurements reflect true (nonrandom) differences. There are three main types of reliability coefficients that can be measured:

1. Stability: the extent to which individuals maintain their relative standings when the same or similar exam is administered twice over a period of time.

2. Equivalence: correlation of scores on two or more forms of the same test by same persons.

3. Internal consistency: correlation between questions on the same test to determine if they measure the same unit.

Simon (2002) further stated that reliable tests may not necessarily be valid tests. Validity, on the other hand, refers to the extent to which measurements achieve the purpose for which they are designed. To ensure the reliability and validity of the survey instrument, a pilot survey was given to 10 patients and 10 physicians prior to the research. The results of the pilot study were not included in the final results. However, results of the pilot study are presented in chapter 4.

Data Analysis

The respondents were instructed to place a check in a box or circle the most appropriate response to the question. This is known as a closed question process. According to Bryman and Bell (2003), closed questions enhance the comparability of

answers, making it easier to show the relationship between variables and to make comparison between respondents or types of respondents.

The completed survey data were entered into SPSS. The researcher used the data to document the statistical significance of the study. Bryman and Bell (2003) stated that statistical significance is solely concerned with the confidence researchers have in their findings. The researcher tested the null hypothesis and determined the statistical significance of the findings regarding the sample. The assumption that there is no difference in the sample groups tested is the null hypothesis. Norusis (2002) stated that since the null hypothesis serves as the frame of reference against which sample results are evaluated, if the sample results appear to be unlikely when the null hypothesis is true, then the null hypothesis should be rejected.

Limitations of Methodology

There are limitations associated with self-completion questionnaires. One limitation is that the researcher cannot ask the respondent to elaborate on a response to a question. Another limitation is that the researcher must limit the number of questions asked; otherwise, there is a risk of not having all the questions answered. Yet another limitation of a self-completion questionnaire survey is the probability of partially answered questions or unanswered questions.

Bryman and Bell (2003) suggested that respondents are able to read the whole questionnaire before answering the first question. When this occurs, none of the questions asked is truly independent of others. It also means that the researcher cannot be sure that questions have been answered in the correct order.

According to Leedy and Ormrod (2005), a weakness of self-reported data is that some participants may intentionally misrepresent their prior experiences and or current behaviors. The researcher relied on the respondents to correctly interpret the survey questions and to give honest responses to the questions.

Strategies for Minimizing Bias

As stated by Leedy and Ormrod (2005), nonrespondents to questionnaires are often different from respondents in one or more ways. They may have less interest in the topic being studied. They may have illnesses, disabilities, or language barriers that prevent them from responding. The researcher acknowledges that research bias may exist in the research due to the different educational levels of the respondents as well as the response rate of the participants.

Summary

This chapter presented a synopsis of the methodology for the study. In addition, the chapter included a synopsis of the study design. A discussion of the population and sample was presented, as were the instrumentation, data collection, and data analysis.

CHAPTER 4. RESULTS

To ensure validity and reliability of the survey instrument, a pilot study was conducted with physician and patient participants. The pilot study included diverse responses from physicians and patients, which allowed the opportunity to capture varying perceptions regarding HIPAA among physicians and patients. A total of 20 individuals participated in the pilot study, which was conducted on June 16, 2007. The reliability of the study was established by determining the p value of < 0.05 when responses of physicians and patients were compared. Content and validity were established by the respondents' feedback.

The purpose of this study was to examine if physicians (the providers of healthcare) and patients (the consumers of healthcare) had similar perceptions of HIPAA. A survey was conducted requesting both patients and providers to complete a questionnaire regarding their demographic characteristics and perceptions of different aspects of HIPAA. The same survey was administered to both the patients and the physicians. The main hypothesis proposed for this study was to determine whether there was a difference in the perception of HIPAA between providers of healthcare and consumers of healthcare. In order to analyze this, the following subhypotheses were tested:

Hypothesis A: There is a difference in the perception of the privacy aspect of HIPAA between providers and consumers of healthcare.

Hypothesis B: There is a difference in the perception of the confidentiality/disclosure rule of HIPAA between providers and consumers of healthcare.

Hypothesis C: There is a difference in the perception of the patient care aspect of HIPAA between providers and consumers of healthcare.

This chapter presents the findings of the results and provides descriptive statistics of the demographic profiles and professional characteristics of the participants, and the inferential statistics of the tests conducted on the data. All tests were conducted at the 0.05 level of significance.

Descriptive Statistics

A total of 970 surveys were distributed (920 to patients and 50 to physicians/providers). Of the 970, 300 patients and 49 physicians/providers participated, resulting in response rates of 33% and 98%, respectively. A description of the demographic and professional characteristics of the physicians/providers who responded is provided in Tables 3 and 4.

The majority of respondents were men (77.55%). More than half of the respondents (58%) were European Americans, while the remainder were distributed across several ethnicities. Most of the respondents were in the peak of their productive years, between the ages of 40 and 60 (60%).

Table 3. Demographic Profiles of Physicians

Variable	Valid *N*	%
Gender		
Female	11	22.6
Male	38	77.4
Ethnicity		
African American	4	8.0
European American	29	58.0
Arab American	4	8.0
Asian American	6	12.0
Hispanic	2	4.0
Other	5	10.0
No response	0	0.0
Age		
40 and under	9	18.0
41–50	15	30.0
51–59	15	30.0
60 and over	11	22.0

Table 4. Professional Characteristics of Physicians

Variable	Valid *N*	%
Number of years in practice		
5 years or fewer	6	12.2
6–15 years	15	30.6
16 years or more	28	57.1
Type of practice		
Primary care	12	24.0
Internist	3	6.0
Specialist	33	66.0
Other	2	4.0
Number of patients seen per week		
0–40	23	46.0
41–90	19	38.0
> 90	8	16.0
Organizational size (number of physicians in organization)		
1	9	18.4
2–5	25	51.0
6–10	15	30.6

Accordingly, more than half (57.14%) have been in practice for more than 15 years. Physicians were mostly either specialists (66%) or primary care physicians (24%). The weekly patient load was moderate, with nearly half of the physicians seeing fewer than 40 patients per week. Finally, the majority of surveyed physicians worked in group practices that were medium (51.2%) to large (30.61%) in size rather than working in solo practice.

A description of the demographic and professional characteristics of patient respondents is provided in Tables 5 and 6. Unlike the results for the physicians/providers, both genders were equally represented in the patient sample. Nearly half of the respondents (42.86%) were European Americans and close to a third (27.57%) were African Americans. Patients in the sample represented a wide spectrum of age groups, with the largest subgroup being those over 60 (35.77%). More than half of the patients (55.99%) were married and about a quarter were either never married (15.86%) or widowed (9.39%).

The two main categories of employment status for the patient sample were employment by someone else (43.51%) or retirement (31.17%), which is in accordance with the large percentage of patients over 60 years of age. The educational level of respondents in the patient group showed that 33.22% of patients graduated from high school, 25.65% had some college education, and 21.67% completed college. There were few patients who had completed professional school or who had attended technical school. Household income revealed a wide spectrum of income levels that mimicked a normal distribution, with most patients earning in the range of $30,000–50,000 a year.

Table 5. Demographic Characteristics of Patients

Variable	Valid *N*	%
Gender		
Female	178	56.9
Male	131	43.1
Ethnicity		
African American	83	27.5
European American	129	42.9
Arab American	9	3.0
Asian American	10	3.3
Hispanic	8	2.7
Other	54	17.9
No response	8	2.7
Age		
40 and under	63	20.5
41–50	55	17.9
51–59	70	22.8
60 and over	119	38.8
Marital status		
Married	173	56.0
Cohabitating	11	3.6
Divorced or separated	45	14.6
Widowed	29	9.4
Never married	49	15.9
No response	2	0.5

Descriptive analyses of all the aspects of HIPAA are shown in Table 7. The findings shown in Table 6 were not described in detail in this section since a more in-depth description and interpretation is provided in the hypothesis testing section of this chapter.

Inferential Statistical Findings

Pearson's cross-tabulations chi-square tests for significant differences were conducted to determine if the proportions of patient and physician responses were similar

across different categories of answers to the same question. The three main aspects of HIPAA compliance are privacy, confidentiality/disclosure, and patient care. Each proposed subhypothesis addressed these three main aspects.

Table 6. Professional Characteristics of Patients

Variable	Valid *N*	%
Employment		
Self-employed	35	11.4
Employed by someone else	134	43.6
Retired	96	31.3
Unemployed	34	11.1
No response	8	2.6
Education		
None or Grades 1–8	13	4.3
High school	101	33.2
Technical/vocational school	18	5.9
Some college	78	25.7
College graduate	66	21.7
Postgraduate	13	4.3
Professional school	12	3.9
No response	3	1.0
Household income ($)		
Less than 10,000	16	5.5
10,001–20,000	19	6.6
20,001–30,000	41	14.2
30,001–40,000	58	20.1
40,001–50,000	56	19.4
50,001–75,000	40	13.8
75,001–100,000	33	11.4
More than 100,000	26	9.0

Table 7. HIPAA Compliance/Disclosure Perception

	Physician		Patient	
Questions/statements	Valid *N*	%	Valid *N*	%
1. Familiarity with Federal Privacy Rule				
Not aware	2	0.04	42	0.14
Aware it exists, not aware of requirements	7	0.14	76	0.25
Somewhat familiar with requirements	25	0.50	109	0.36
Very familiar with its requirements	16	0.32	73	0.24
2. Is there a complaint mechanism for privacy breaches?				
Yes	40	0.80	71	0.24
No	1	0.02	17	0.06
Don't know	9	0.18	206	0.70
3. Do you believe that violation of information privacy is a serious problem?				
Strongly agree	16	0.32	105	0.35
Agree	24	0.48	88	0.29
Neutral	7	0.14	46	0.15
Disagree	3	0.06	13	0.04
Strongly disagree	0	0.00	4	0.01
Unsure	0	0.00	44	0.15
4. Do you believe that withholding a patient's protected health information in order to comply with HIPAA can impact patient care?				
Strongly agree	14	0.28	73	0.25
Agree	22	0.44	97	0.33
Neutral	7	0.14	40	0.14
Disagree	1	0.02	28	0.09
Strongly disagree	5	0.10	1	0.00
Unsure	1	0.02	57	0.19
5. Have you discussed confidentiality with patients?				
Never	2	0.04	114	0.38
Rarely	21	0.43	54	0.18
Sometimes	23	0.47	75	0.25
Often	2	0.04	21	0.07
Very often	1	0.02	8	0.03
Unsure	0	0.00	25	0.08
6. Have any of your patients expressed a concern about confidentiality?				
Never	19	0.39	235	0.79
Rarely	25	0.51	19	0.06
Sometimes	4	0.08	23	0.08
Often	1	0.02	6	0.02
Very often	0	0.00	5	0.02
Unsure	0	0.00	8	0.03

Table 7. HIPAA Compliance/Disclosure Perception (*continued*)

Questions/statements	Physician		Patient	
	Valid *N*	%	Valid *N*	%
7. Have any of your patients asked to review their records?				
Never	24	0.49	165	0.55
Rarely	19	0.39	49	0.16
Sometimes	4	0.08	44	0.15
Often	1	0.02	24	0.08
Very often	1	0.02	6	0.02
Unsure	0	0.00	14	0.05
8. Have any of your patients asked to amend their records?				
Never	39	0.80	259	0.86
Rarely	10	0.20	11	0.04
Sometimes	0	0.00	12	0.04
Often	0	0.00	2	0.01
Very often	0	0.00	1	0.00
Unsure	0	0.00	16	0.05
9. Do you disclose patient health information to the patient's family?				
Never	7	0.15	150	0.50
Rarely	8	0.17	21	0.07
Sometimes	17	0.35	66	0.22
Often	15	0.31	13	0.04
Very often	1	0.02	6	0.02
Unsure	0	0.00	45	0.15
10. Do you ever disclose patient health information to the patient's employer?				
Never	34	0.69	202	0.72
Rarely	5	0.10	4	0.01
Sometimes	10	0.20	11	0.04
Often	0	0.00	6	0.02
Very often	0	0.00	1	0.00
Unsure	0	0.00	57	0.20
11. Do you ever disclose patient health information to the patient's insurer?				
Never	30	0.61	59	0.20
Rarely	9	0.18	11	0.04
Sometimes	7	0.14	23	0.08
Often	1	0.02	11	0.04
Very often	1	0.02	16	0.05
Unsure	1	0.02	181	0.60

Table 7. HIPAA Compliance/Disclosure Perception (*continued*)

Questions/statements	Physician		Patient	
	Valid *N*	%	Valid *N*	%
12. Do you ever disclose patient health information to a pharmaceutical company?				
Never	6	0.12	125	0.42
Rarely	43	0.88	5	0.02
Sometimes	0	0.00	19	0.06
Often	0	0.00	3	0.01
Very often	0	0.00	0	0.00
Unsure	0	0.00	145	0.49
13. Do you have written privacy policies in your organization?				
Yes	42	0.86	223	0.75
No	0	0.00	10	0.03
Unsure	8	0.16	60	0.20
14. Do you require written authorization of non-routine use of patient privacy information?				
Yes	38	0.78	167	0.56
No	3	0.06	15	0.05
Unsure	8	0.16	114	0.39
15. Do you feel HIPAA will help physicians?				
Yes	2	0.04	79	0.27
No	30	0.63	60	0.20
Unsure	16	0.33	154	0.53
16. How do you rate your organization's performance in protecting patient confidentiality?				
Very good	28	0.58	128	0.44
Good	17	0.35	61	0.21
Fair	2	0.04	12	0.04
Poor	0	0.00	3	0.01
Unsure	1	0.02	90	0.31
17. How do you rate your organization's effectiveness in preventing privacy policies from interfering with physicians' ability to provide good care to patients?				
Very good	12	0.24	88	0.30
Good	24	0.48	67	0.23
Fair	12	0.24	14	0.05
Poor	2	0.04	4	0.01
Unsure	0	0.00	120	0.41
18. How do you rate your organization's effectiveness in preventing privacy policies from interfering with physicians' ability to consult with colleagues?				
Very good	19	0.38	81	0.28
Good	12	0.24	58	0.20
Fair	17	0.34	16	0.05
Poor	2	0.04	7	0.02
Unsure	0	0.00	130	0.45

Table 7. HIPAA Compliance/Disclosure Perception (*continued*)

Questions/statements	Physician		Patient	
	Valid *N*	%	Valid *N*	%
19. Do you control access to patient medical information?				
Yes	42	0.84	146	0.50
No	7	0.14	18	0.06
Unsure	1	0.02	129	0.44
20. In your organization, is patient medical information ever disclosed without patient consent?				
Never	35	0.70	129	0.44
Rarely	12	0.24	3	0.01
Sometimes	3	0.06	6	0.02
Often	0	0.00	1	0.00
Very often	0	0.00	5	0.02
Unsure	0	0.00	148	0.51
21. Are patient medical records locked when stored?				
Yes	35	0.70	55	0.19
No	8	0.16	15	0.05
Unsure	7	0.14	223	0.76

Findings for Hypothesis A

$H1A_0$: There is no significant difference in the perception of the privacy aspect of HIPAA between providers and consumers of healthcare.

$H1A_A$: There is a difference in the perception of the privacy aspect of HIPAA between providers and consumers of healthcare.

The findings for the chi-square tests are shown in Table 8. For the privacy familiarity/practice aspect of the HIPAA, five questions (1, 2, 3, 13, and 14) were clustered to examine whether the two groups differed with respect to perceptions of privacy familiarity and practice. First, when asked about familiarity with this federal privacy rule, there was a larger percentage of physicians who expressed that they were somewhat familiar (50%) to very familiar (32%) with its requirements.

Table 8. Privacy Perceptions of Patients and Physicians

HIPAA question	Chi-square (p value)
1. Familiarity with Federal Privacy Rule	0.032*
2. Is there a complaint mechanism for privacy breaches?	0.000*
3. Do you believe that violation of information privacy is a serious problem?	0.023*
13. Do you have written privacy policies in your organization?	0.289
14. Do you require written authorization of non-routine use of patient privacy information?	0.011*

*Statistically significant for $p < 0.05$.

On the other hand, patients expressing the same level of familiarity were 36% and 24%, respectively. The chi-square statistical test showed that these differences in familiarity with HIPAA requirements were statistically significant ($p = 0.032$). This discrepancy grew substantially when patients and physicians were asked about whether there was a complaint mechanism for privacy breaches. with only 18% of physicians who did not know and 70% of patients who did not know ($p = 0.000$). A similar pattern was noticed with a large percentage of patients being unsure about HIPAA privacy aspects, with statistical significance between the two groups, for belief that violation of information privacy is a serious problem (15% vs. 0%, $p = 0.023$). These results represent physician and patient knowledge of whether the requirement of written authorization of nonroutine use of patient privacy information is presented to the patient in the physician's office (39% vs. 16%, $p = 0.011$). In only one instance, knowledge of presence of written privacy policies in the organization, were patient and physician findings not statistically significantly different ($p = 0.289$).

According to these findings, the null subhypothesis $H1A_0$ was rejected and the alternative was accepted, except in the case of knowledge of presence of written privacy policies in the organization, where the null was accepted. The results are also displayed in graph format in Appendix B.

Findings for Hypothesis B

$H1B_0$: There is no significant difference in the perception of the confidentiality/disclosure rule of HIPAA between providers and consumers of healthcare.

$H1B_A$: There is a significant difference in the perception of the confidentiality/disclosure rule of HIPAA between providers and consumers of healthcare.

Patients and physicians were asked a number of questions to examine whether the two groups differed with respect to confidentiality/disclosure. The results are displayed in Table 9, and all show a statistically significant difference between physicians and patients. Discussion of confidentiality was reported in 38% of patients as *never* and 18% as *rarely*, while most of the physicians reported discussing with their patients *rarely* (43%) and *sometimes* (47%). In addition, patients expressed much less concern about confidentiality, with 79% indicating that they were never concerned about confidentiality, while in the case of physicians, this percentage was 39%. Also noteworthy is response to the statement "feeling that HIPAA will help physicians." About two thirds of physicians replied that they felt such a rule would not help physicians, while only 20% of patients felt so.

A consistent trend was observed in a number of HIPAA attributes with respect to confidentiality/disclosure. Questions 5–12, 15, 16, and 19–21 on the survey were clustered for the confidentiality/disclosure aspect. Findings for responses to these

questions showed a large percentage of patients reported being unsure while only a very small percentage of physicians reported such unsure status. In addition, all of these differences were highly statistically significant (see Table 9).

Table 9. Confidentiality/Disclosure Perceptions of Patients and Physicians

HIPAA questions	Chi-square (p value)
5. Discussion of confidentiality with patients	0.000*
6. Patient's expression a concern about confidentiality	0.000*
7. Patients asking to review their records	0.005*
8. Patients asking to amend their records	0.000*
9. Disclose of patient health information to the patient's family	0.000*
10. Disclose of patient health information to the patient's employer	0.000*
11. Disclose of patient health information to the patient's insurer	0.000*
12. Disclose of patient health information to a pharmaceutical company	0.000*
15. Feeling that HIPAA will help physicians	0.000*
16. Rating organization's performance in protecting patient confidentiality	0.001*
19. Control of access to patient medical information	0.000*
20. Disclosure of patient medical information without patient consent	0.000*
21. Locked patient medical records when stored	0.000*

*Statistically significant for $p < 0.05$.

Based on these results, the null subhypothesis $H1B_0$ was rejected and alternative subhypothesis accepted, which states that there is a difference in the perception of the

confidentiality/disclosure aspect of HIPAA between providers and consumers of healthcare. The results are also displayed in graph format in Appendix B.

Findings for Hypothesis 1C

$H1C_0$: There is no significant difference in the perception of the patient care aspect of HIPAA between providers and consumers of healthcare.

$H1C_A$: There is a significant difference in the perception of the patient care aspect of HIPAA between providers and consumers of healthcare.

Three questions were asked of patients and physicians to examine whether the two groups differed with respect to patient care. The results are displayed in Table 10. First, when asked about belief that withholding a patient's protected health information in order to comply with HIPAA can impact patient care, there was a statistical difference ($p = 0.000$) between patients and physicians.

Table 10. Patient Care Perceptions of Patients and Physicians

HIPAA question	Chi-square (p value)
4. Belief that withholding a patient's protected health information in order to comply with HIPAA can impact patient care.	0.000*
17. Rating organization's effectiveness in preventing privacy policies from interfering with physicians' ability to provide good care to patients.	0.000*
18. Rating organization's effectiveness in preventing Privacy Policies from interfering with physicians' ability to consult with colleagues.	0.000*

* Statistically significant for $p < 0.05$.

As can be clearly noticed, the biggest distribution difference between the two groups was within the *unsure* category. While only 2% of physicians were unsure about impact on patient care, 19% of patients were unsure. This trend was observed for the other two questions, and in both questions the results indicated statistically significant difference. When rating organizations' effectiveness in preventing privacy policies from interfering with physicians' ability to provide good care to patients and when rating organizations' effectiveness in preventing privacy policies from interfering with physicians' ability to consult with colleagues, the percent of patients who indicated being unsure was, respectively, 31% and 41%, which are both much higher than 2% and 0%, respectively.

Based on these results, the null subhypothesis $H1C_o$ was rejected and alternative subhypothesis accepted, which states that there is a difference in the perception of the patient care aspect of HIPAA between providers and consumers of care. The results are also displayed in graph format in Appendix B.

Summary

In this chapter, descriptive statistics of the surveyed consumers and providers of healthcare samples were provided, and testing of the hypotheses was conducted with findings discussed. The surveyed sample can be described as representative of the target population. Patients represented a wide spectrum of ethnicity, age, and household income, and were equally representative with respect to gender. Physicians represented the still-male-dominated medical profession. Except for one particular aspect of HIPAA, there appeared to be significant differences between consumers of healthcare and providers of

healthcare. As a result, the main null hypothesis was rejected and the alternative hypothesis accepted.

The next chapter includes a summary of the study. A discussion of the findings and conclusion are presented. In addition, recommendations for future research are included.

CHAPTER 5. RESULTS, CONCLUSIONS, AND RECOMMENDATIONS

This research was designed to further the understanding of physicians' and patients' perceptions of HIPAA and to determine if physicians' perceptions and understanding of the HIPAA rules can impact patient care. This chapter is presented in three sections. The first section is a summary of the major findings of the study. The second section discusses the findings of the research with an examination of the limitations of the study. The chapter concludes with a summary of the implications and recommendations for future research.

Discussion

The purpose of this research study was to investigate the perspectives of physicians and patients regarding the role of HIPAA privacy regulations in protecting confidential health information as well as the impact the rule may have on the quality of patient care. The main hypothesis for this study was to determine if there was a difference in the perception of HIPAA between physicians and patients. In order to make this determination, three subhypotheses were tested regarding privacy, confidentiality/disclosure, and patient care.

Hypothesis $A1A_0$ stated, "There is no significant difference in the perception of the privacy aspect of HIPAA between providers and consumers of healthcare." This

study rejected the null subhypothesis and accepted the alternative $H1A_A$, which stated ,"There is a difference in the perception of the privacy aspect of HIPAA between providers and consumers of healthcare." The research indicated that 82% of physician respondents were familiar with the privacy aspects of HIPAA, which is consistent with the literature. Slutsman, Kass, McGready, and Wynia (2005) indicated in their study that 89% of the physicians in their survey were familiar with HIPAA. Conversely, 60% of the patients in this research survey expressed the same level of familiarity of the HIPAA Rule; some patients expressed serious concerns regarding the privacy aspects of HIPAA. For example, one patient respondent stated

> Privacy is an important issue; however, I feel that HIPAA regulations have gone too far and my physician before HIPAA never revealed any information regarding my medical information without my knowledge or permission. I hate having to sign this paper every time I have a procedure done at the same place, such as a blood draw.

Another patient surveyed commented, "I have serious concerns that all of my information is available to the insurance company, yet withheld from family members. It seems as if HIPAA weighs in favor of big business." The literature suggests that consumers/patients are concerned about the protection and privacy of their personal health information.

Bishop, Holmes, and Kelley (2005) suggested that despite new federal protections, consumers are still anxious about the privacy of their personal health information and misinformed about their rights under HIPAA. This study supported Bishop et al. and revealed that 70% of the patients who participated in the study were unaware if there was a complaint mechanism for breaches of privacy regarding protected health information. However, only 18% of the physicians surveyed were not aware of a complaint mechanism for privacy breaches of protected health information. In this research, some

patients expressed concern regarding an explanation of their rights pertaining to HIPAA. For example, a patient respondent commented

> I get a pamphlet and they ask me to sign a form, but it is intermixed with so many other forms to complete, I do not get a chance to read it. It is never clearly explained to me as a patient.

According to Yang and Kombarakaran (2006), all providers of healthcare services must notify their patients in writing regarding their policies, which must include the patient's right to complain to the Health and Human Services OCR, on the release and transmittal of Protected Health Information.

Hypothesis $1B_0$ stated, "There is no significant difference in the perception of the confidentiality/disclosure rule of HIPAA between physicians and consumers of healthcare." The null subhypothesis $H1B_0$ was rejected and the alternative subhypothesis was accepted, which stated that there is a difference in the perception of the confidentiality/disclosure aspect of HIPAA between physicians and consumers of healthcare. This study showed that 79% of the patients were not concerned about confidentiality/disclosure, which suggests that there is a significant degree of patient-physician trust. For example, one of the physician respondents stated, "Health information is discussed with family members when requested by the patient." Yet another patient respondent wrote, "The idea of sharing medical information with other treating physicians should happen naturally. I assume information goes to the insurers for payment purposes." This is consistent with the literature findings. Bishop et al. (2005) stated that almost all respondents involved in their survey were willing to share protected health information with physicians involved in their care. However, less than one third

were willing to share protected health information with health professionals not directly involved in their care.

On the other hand, this research indicated that 39% of the physicians responded that they were not concerned about confidentiality/disclosure. Some of the comments of physician respondents in this survey were: "Patient permission must be secured in writing before I share information with the family" and

> Anytime patient privacy acts to prevent one physician from obtaining information pertaining to patient care from physicians not directly involved in the patient care, there is a problem. Among physicians, patient information should be able to be shared when necessary without fear of violating patient privacy rules.

According to the literature, disclosures are permitted for treatment, payment, and healthcare operations. Yang and Kombarakaran (2006) stated no client consent is required for routine disclosures, although all other uses of information are prohibited without a specific consent. The information that may be disclosed is based on professional judgment regarding what is the minimum necessary information for its intended use. They further stated that limited, unavoidable, incidental disclosures that occur in the course of routine operations do not constitute violations.

Hypothesis $1C_0$ stated, "There is no significant difference in the perception of the patient care aspect of HIPAA between providers and consumers of healthcare." The null subhypothesis Hypothesis $1C_0$ was rejected and the alternative subhypothesis was accepted, which stated that there is a difference in the perception of the patient care aspect of HIPAA between providers and consumers of healthcare. This study indicated that 19% of the patient respondents were unsure if HIPAA had an impact on the quality of patient care, while 2% of the physicians were unsure. On the other hand, this research

indicated that more than 58% of the patients believe that withholding a patient's protected health information in order to comply with HIPAA can impact patient care. Likewise, more than 72% of the physician respondents believe that withholding a patient's protected health information in order to comply with HIPAA can impact patient care.

Some of the patient respondents comments were: "When we have tests done in Florida, the privacy law prevents Michigan doctors from getting quick access to medical information" and

> I found much difficulty getting my records from the hospital to my physician due to stringent privacy practices. I am not aware of colleague-to-colleague information sharing regarding my records. When files are released for insurance purposes or for transfer from one physician to another, they ask for a signature in person.

Some of the physician respondent comments regarding the HIPAA impact on the quality of patient care were as follows: "Laws can be made user-friendly and reduce the delay in providing care. One way is that patients keep their own records, either electronically, disk, etc." and "Information is only disclosed with written authorization." This is consistent with existing literature regarding the HIPAA impact on the quality of patient care. Jacobson (2002) stated that the regulation does not by its terms clearly permit covered entities to share HIPAA- protected health information for disease management and care coordination purposes unless, of course, cumbersome and expensive patient authorizations are obtained. Jacobson further stated that the HIPAA Privacy Rule, even after the Bush administration's recent modifications may bar physicians and other providers from disclosing critically important patient-identifiable

health information (protected health information) to entities that coordinate care for the chronically ill.

In conclusion, consumers of healthcare/patients and physicians have different perceptions of the HIPAA Privacy Rule. They also differ in their perceptions of confidentiality/disclosure. Patients, for the most part, trust that their physicians will not disclose any of their protected health information without their consent. Finally, both the physicians and patients differed on the impact of HIPAA with regard to the effect on the quality of care.

This study contributes to the literature in the following ways: (a) the study provides additional research on the impact of the quality of patient care resulting from the interpretation and implementation of the HIPAA Rule by physicians, (b) the study focuses on the perceptions of patients and physicians regarding privacy and confidentiality questions as well as other researchers' findings regarding this important issue, and (c) this research reveals the need to further educate patients regarding their privacy rights.

Limitations

This research targeted private practice physicians and consumers of care/patients for those private practice physicians. This limitation prevented representation from physicians in hospital healthcare systems and their patients as well as university-based healthcare systems physicians and their patients. Another limitation of the study was that the majority of the physicians surveyed were specialists. This limitation did not allow

input from family practice physicians. Last, the study did not focus on culture, education, or gender differences.

Recommendations

General Recommendations

This study focused on the perceptions of the HIPAA Privacy Rule of physicians and consumers of healthcare/patients. In addition, the research sought to determine if the HIPAA Privacy Rule impacts the quality of patient care. This research suggested that there is a difference in the perception of the privacy aspect of the HIPAA Rule among physicians and patients and there is a difference in the confidentiality/disclosure perceptions of HIPAA regarding physicians and patients. This study and the literature revealed that physicians and patients perceive that the HIPAA Rule may impact the quality of healthcare. This is primarily due to the fact that the HIPAA Rule is open for interpretation and application by physicians. The recommendation is to nationally standardize the HIPAA guidelines, which will leave limited room for interpretation; therefore, the application of the rule will be uniform. Another recommendation is to educate in depth the patients as well as physicians regarding the HIPAA Privacy Rule. One way that this can be done is for the U.S. Department of Health and Human Services to produce and distribute an educational DigitalVideoDisk (DVD) to physicians and to have patients, staff, and physicians view and sign-off that they have a thorough understanding of the information presented. The fact that 18% of the physicians surveyed for this study did not know if there is a complaint mechanism for HIPAA breaches demonstrates the need for in-depth physician education. All physicians should be aware

of the complaint mechanism for HIPAA breaches, since they interpret and implement the rules.

Recommendations for Future Research

Determine if HIPAA perceptions differ as the result of age, ethnic, or gender differences. Determine if there are differences in the perception of the Privacy Rule as a result of education and locale (urban and suburban, geographic locations within the United States). Compare the perceptions of private practice physicians and patients and hospital-based physicians and patients. Compare the difference between the U.S. system with another technologically advanced country with regard to privacy and confidentiality of protected health information.

Summary

The objective of this study was to determine if differences exist between physicians and patients regarding knowledge of privacy and confidentiality of protected health information. This research also sought to determine if the perceptions of physicians regarding HIPAA affect the quality of patient care.

The study established that

1. 82% of physicians were familiar with the HIPAA Rule, while 70% of patients were familiar.

2. 18% of the physicians did not know whether there was a complaint mechanism for breaches of HIPAA, while 70% of patients did not know.

3. 15% of the physicians believed that a violation of HIPAA is a serious problem, while 0% of the patients did.

4. 30% of the physicians had knowledge of written authorization required by the patient for nonroutine use of patient protected health information, while 16% of the patients were aware of this requirement.

5. 90% of the physicians indicated that they had discussed confidentiality with their patients, while 56% of patients indicated that confidentially had been discussed with them by their physicians.

6. 39% of the physicians were not concerned about confidentiality, while 79% of the patients were not concerned.

7. 86% of physicians felt that withholding patient protected health information in order to comply with HIPAA can impact quality patient care, compared to 72% of the patients.

This final chapter provided a discussion and review of the major findings of this research in relation to the hypothesis and research question. General recommendations and recommendations for future research were also presented.

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APPENDIX A. DATA COLLECTION INSTRUMENTS

Healthcare Provider (Physician) HIPAA Survey
(Health Insurance Portability and Accountability Act)

Please answer the following by either checking the box or writing your response.

1. Gender
   - □ Female
   - □ Male

2. Ethnicity
   - □ African American
   - □ European American
   - □ Arab American
   - □ Asian American
   - □ Hispanic
   - □ Other
   - □ Unsure/refused

3. Age
   - □ 40 and under
   - □ 41–50
   - □ 51–59
   - □ 60 and over

4. Number of years in practice
   - □ 5 years or less
   - □ 6–15 years
   - □ 16 years or more

5. Type of Practice
   - □ Primary Care
   - □ Internist
   - □ Specialist
   - □ Other

6. Number of patients seen per week
   - □ 0–40
   - □ 41–90
   - □ >90

7. Familiarity with Federal Privacy Rule
   - □ Not aware
   - □ Aware it exists but not aware of requirements
   - □ Somewhat familiar with requirements
   - □ Very familiar with its requirements

8. Is there a complaint mechanism for privacy breaches
   - □ Yes
   - □ No
   - □ Don't know

9. Believe that violation of information privacy is a serious problem
   - □ Strongly agree
   - □ Agree
   - □ Neutral
   - □ Disagree
   - □ Strongly disagree
   - □ Unsure

10. Do you believe that withholding a patient's protected health information in order to comply with HIPAA can impact patient care?
   - □ Strongly Agree
   - □ Agree
   - □ Neutral
   - □ Disagree
   - □ Strongly Disagree
   - □ Unsure

11. Organizational size (number of physicians in organization)
   - □ 1
   - □ 2 to 5
   - □ 6–10

12. Have you discussed confidentiality with patients?
   - □ Never
   - □ Rarely
   - □ Sometimes
   - □ Often
   - □ Very Often
   - □ Unsure

13. Have any of your patients expressed a concern about confidentiality
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

14. Have any of your patients asked to review their records?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

15. Have any of your patients asked to amend their records?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

16. Do you disclose patient health information to the patient's family?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

17. Do you ever disclose patient health information to the patient's employer?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

18. Do you ever disclose patient health information to the patient's insurer?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

19. Do you ever disclose patient health information to a pharmaceutical company?
    - □ Yes
    - □ No
    - □ Unsure

20. Do you have written privacy policies in your organization?
    - □ Yes
    - □ No
    - □ Unsure

21. Do you require written authorization of nonroutine use of patient privacy information?
    - □ Yes
    - □ No
    - □ Unsure

22. Do you feel HIPAA will help physicians?
    - □ Yes
    - □ No
    - □ Unsure

23. How do you rate your organization's performance in protecting patient confidentiality.
    - □ Very good
    - □ Good
    - □ Fair
    - □ Poor
    - □ Unsure

24. How do you rate your organization's effectiveness in preventing privacy policies from interfering with physicians' ability to provide good care to patients.
    - □ Very good
    - □ Good
    - □ Fair
    - □ Poor
    - □ Unsure

25. How do you rate your organization's effectiveness in preventing Privacy Policies from interfering with physicians' ability to consult with colleagues.
- □ Very Good
- □ Good
- □ Fair
- □ Poor
- □ Unsure

26. Do you control access to patient medical information?
- □ Yes
- □ No
- □ Unsure

27. In your organization, is patient medical information ever disclosed without patient consent?
- □ Never
- □ Rarely
- □ Sometimes
- □ Often
- □ Very Often
- □ Unsure

28. Are patient medical records locked when stored?
- □ Yes
- □ No
- □ Unsure

29. Is there any other information regarding organizational or physician practices for maintaining the confidentiality of medical information and how this may impact patient care either within your organization or elsewhere that you find interesting or problematic?

Thank you very much for your time and effort in completing this survey.

Consumer (Patient) HIPAA Survey
(Health Insurance Portability and Accountability Act)

Please answer the following by either checking the box or writing your response.

1. Gender
   - □ Female
   - □ Male

2. Ethnicity
   - □ African American
   - □ European American
   - □ Arab American
   - □ Asian American
   - □ Hispanic
   - □ Other
   - □ Unsure/refused

3. Age
   - □ 18–40
   - □ 41–50
   - □ 51–59
   - □ 60 and over

4. Are you….
   - □ Married
   - □ Living as married
   - □ Divorced or separated
   - □ Widowed
   - □ Never married/single
   - □ Refused

5. Are you….
   - □ Self-employed
   - □ Employed by someone else
   - □ Retired
   - □ Unemployed
   - □ Refused

6. What is the last grade or class that you completed?
   - □ None or Grades 1–8
   - □ High School
   - □ Technical or vocational school
   - □ Some college
   - □ College graduate
   - □ Postgraduate
   - □ Professional school
   - □ Unsure/refused

7. Familiarity with Federal Privacy Rule
   - □ Not aware
   - □ Aware it exists but not aware of requirements
   - □ Somewhat familiar with requirements
   - □ Very familiar with its requirements

8. Does you physician have a complaint mechanism for privacy breaches
   - □ Yes
   - □ No
   - □ Don't know

9. Do you believe that violation of information privacy is a serious problem
   - □ Strongly agree
   - □ Agree
   - □ Neutral
   - □ Disagree
   - □ Strongly disagree
   - □ Unsure

10. Do you believe that withholding a patient's protected health information in order to comply with HIPAA can impact patient care?
   - □ Strongly Agree
   - □ Agree
   - □ Neutral
   - □ Disagree
   - □ Strongly Disagree
   - □ Unsure

11. Total household income
    - □ Less than $10,000.00
    - □ $10,000–$20,000.00
    - □ $20,000–$30,000.00
    - □ $30,000–$50,000.00
    - □ $50,000–$75,000.00
    - □ $75,000–$100,000.00
    - □ $100,000 or more
    - □ Unsure/refused

12. Has your physician ever discussed confidentiality with you?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

13. Have you ever expressed a concern about confidentiality with your physician?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

14. Have you ever asked your doctor to review your records?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

15. Have you ever asked your physician to amend your records?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

16. Does your physician disclose your patient health information to your family?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

17. Does your physician ever disclose your patient health information to your employer?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

18. Does your physician ever disclose your patient health information to your insurer?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

19. Does your physician ever disclose your health information to a pharmaceutical company?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

20. To the best of your knowledge does your physician have written privacy policies in his/her office/clinic?
    - □ Yes
    - □ No
    - □ Unsure

21. Does your physician require your written authorization of nonroutine use of your privacy patient information?
    - □ Yes
    - □ No
    - □ Unsure

22. Do you feel HIPAA will help patients?
    - □ Yes
    - □ No
    - □ Unsure

23. How do you rate your physician's organization's performance in protecting your confidentiality as a patient?
    - □ Very good
    - □ Good
    - □ Fair
    - □ Poor
    - □ Unsure

24. How do you rate your physician's organization's effectiveness in preventing privacy policies from interfering with physicians' ability to provide good care to you?
    - □ Very good
    - □ Good
    - □ Fair
    - □ Poor
    - □ Unsure

25. How do you rate your physician's organization's effectiveness in preventing privacy policies from interfering with physicians' ability to consult with colleagues regarding your care?
    - □ Very Good
    - □ Good
    - □ Fair
    - □ Poor
    - □ Unsure

26. Does your physician control access to your patient medical information?
    - □ Yes
    - □ No
    - □ Unsure

27. Is your patient medical information ever disclosed without your consent?
    - □ Never
    - □ Rarely
    - □ Sometimes
    - □ Often
    - □ Very Often
    - □ Unsure

28. Are your medical records locked when stored?
    - □ Yes
    - □ No
    - □ Unsure

29. Is there any other information regarding organizational or physician practices for maintaining the confidentiality of medical information and how this may impact your care either within the physician's organization or elsewhere that you find interesting or problematic?

_____
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Thank you very much for your time and effort in completing this survey.

APPENDIX B. FIGURES FOR RESULTS OF HIPAA QUESTIONNAIRE

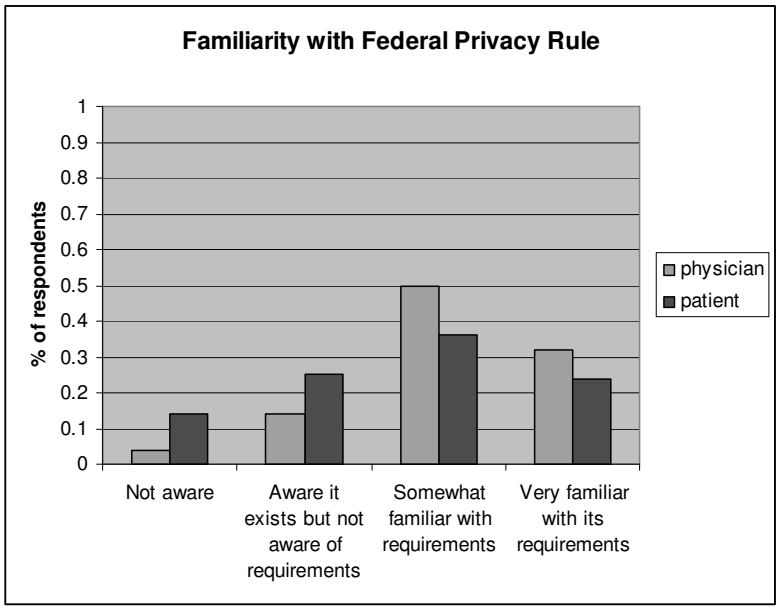

Figure B1. Privacy familiarity/practice perceptions (Q1 of HIPAA).

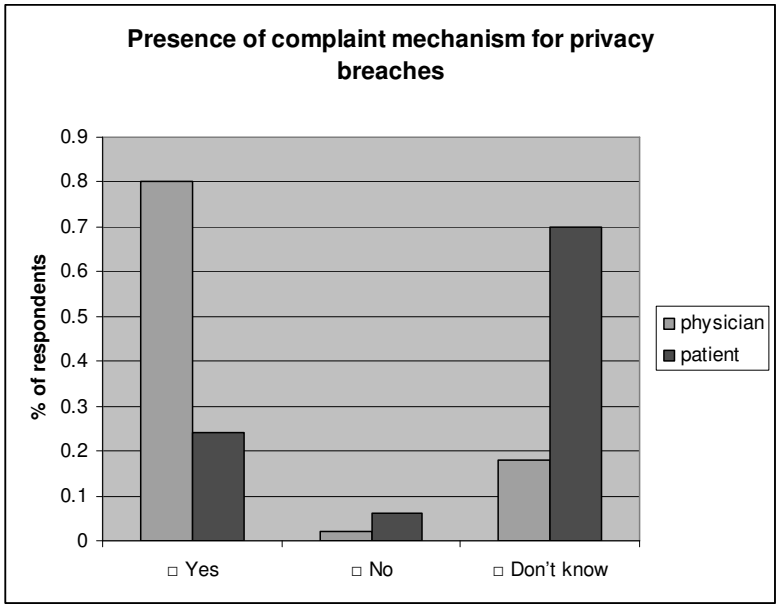

Figure B2. Privacy familiarity/practice perceptions (Q2 of HIPAA).

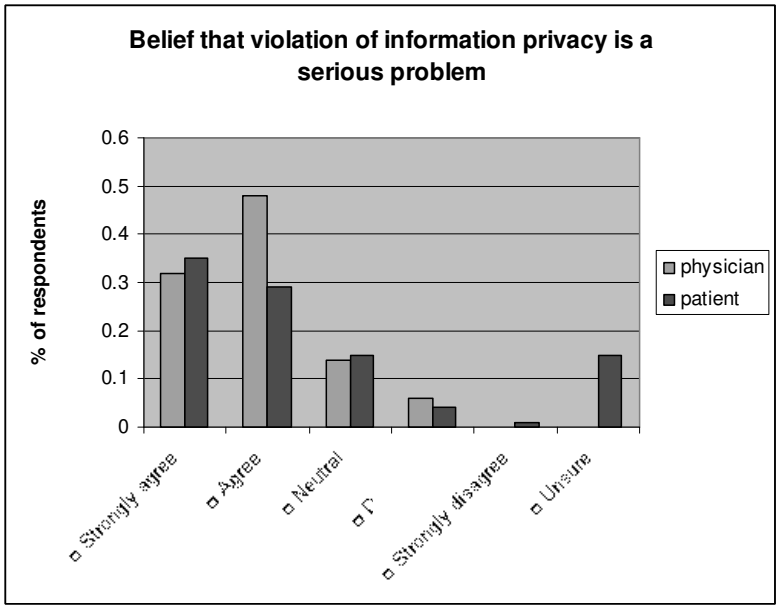

Figure B3. Privacy familiarity/practice perceptions (Q3 of HIPAA).

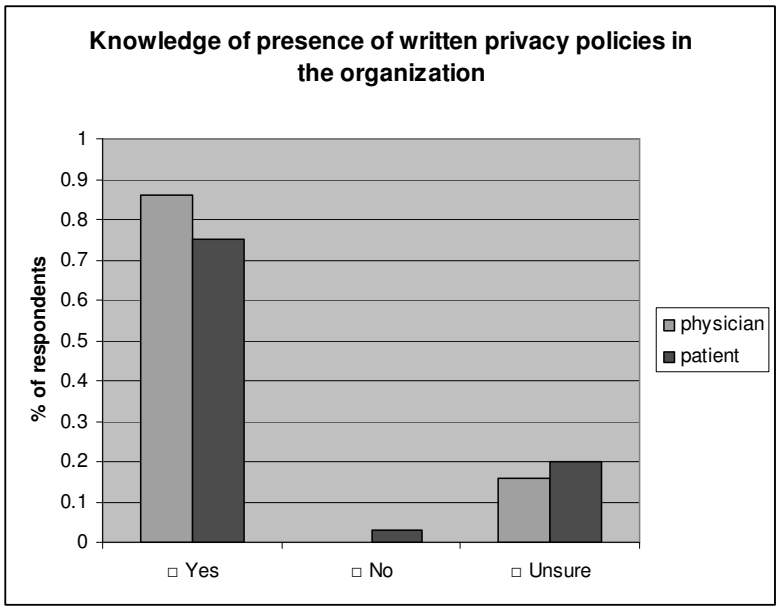

Figure B4. Privacy familiarity/practice perceptions (Q13 of HIPAA).

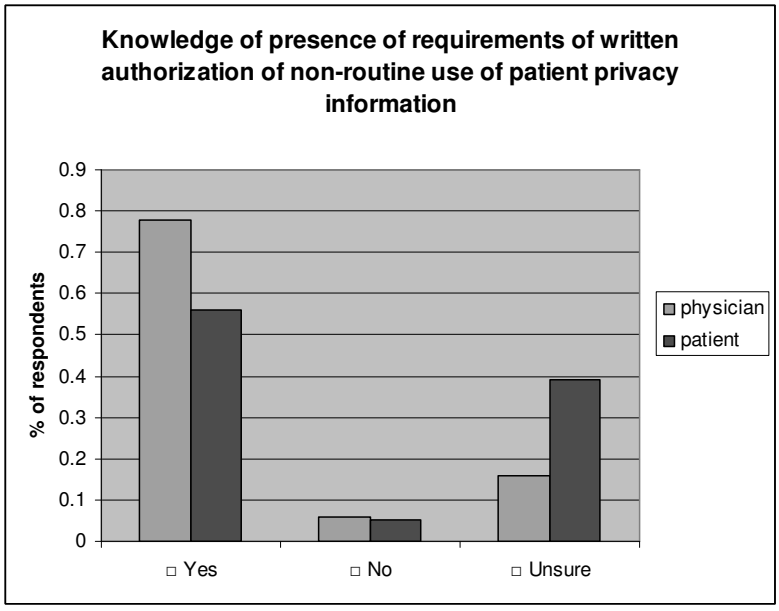

Figure B5. Privacy familiarity/practice perceptions (Q14 of HIPAA).

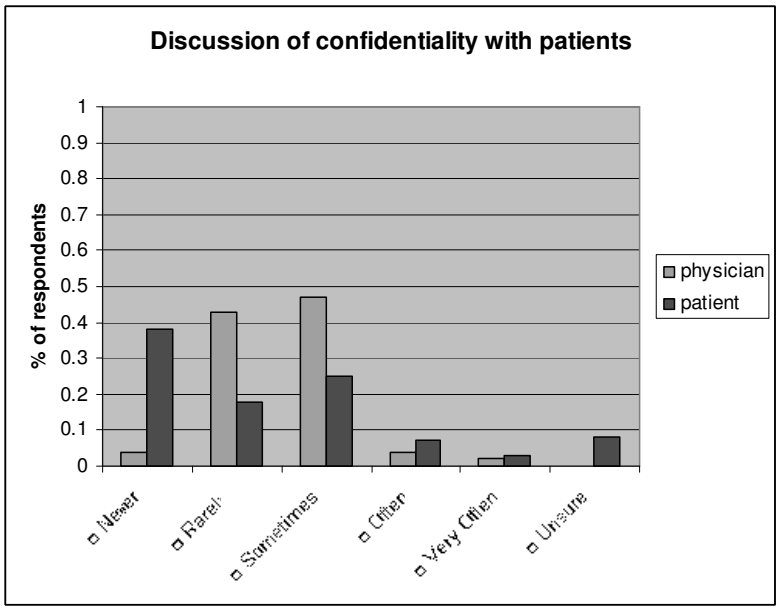

Figure B6. Privacy confidentiality/disclosure perceptions (Q5 of HIPAA).

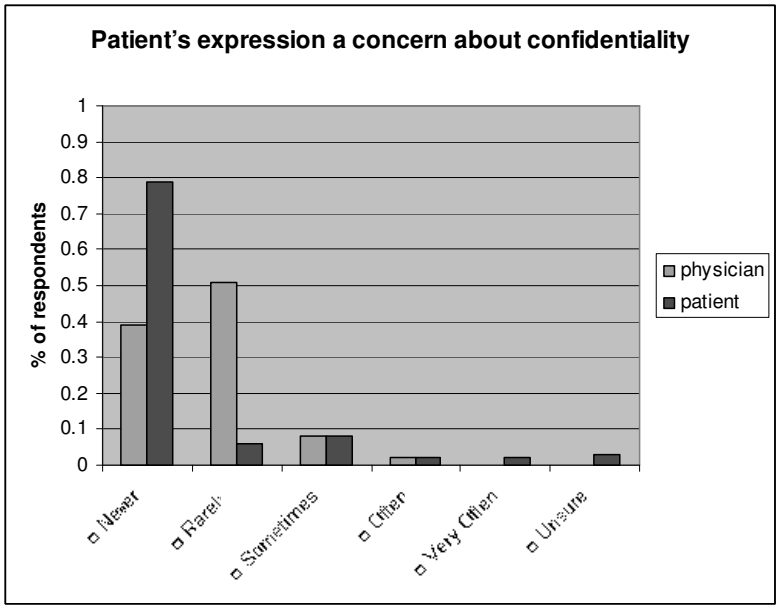

Figure B7. Privacy confidentiality/disclosure perceptions (Q6 of HIPAA).

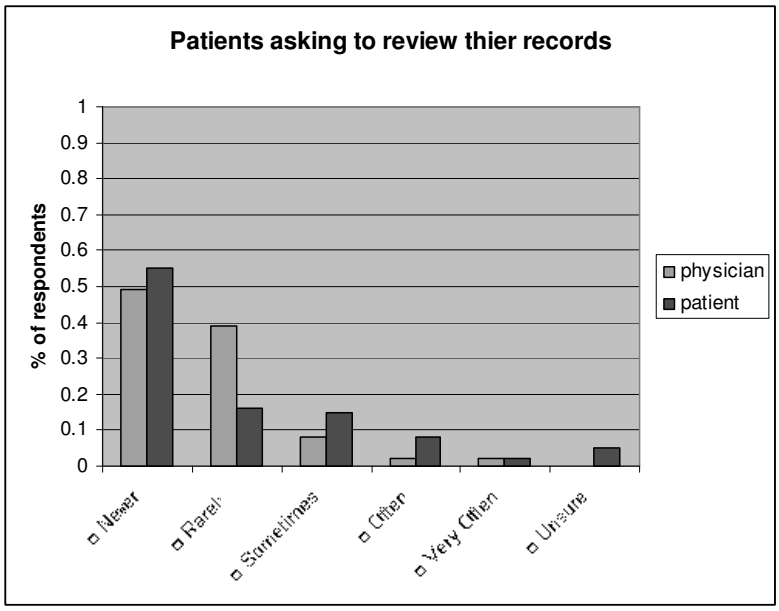

Figure B8. Privacy confidentiality/disclosure perceptions (Q7of HIPAA).

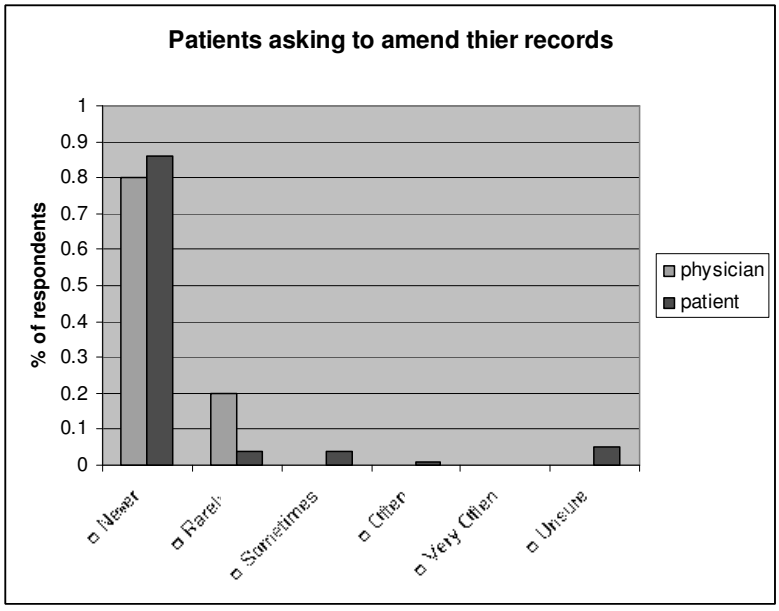

Figure B9. Privacy confidentiality/disclosure perceptions (Q8 of HIPAA).

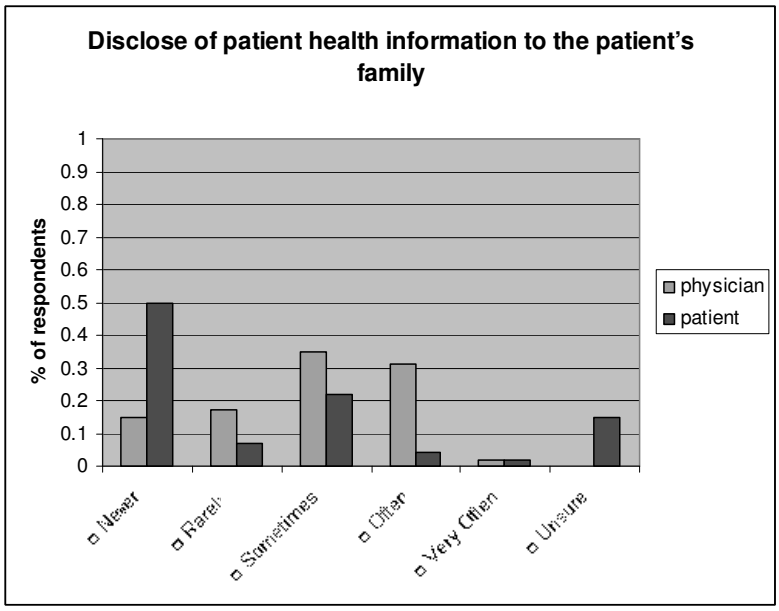

Figure B10. Privacy confidentiality/disclosure perceptions (Q9 of HIPAA).

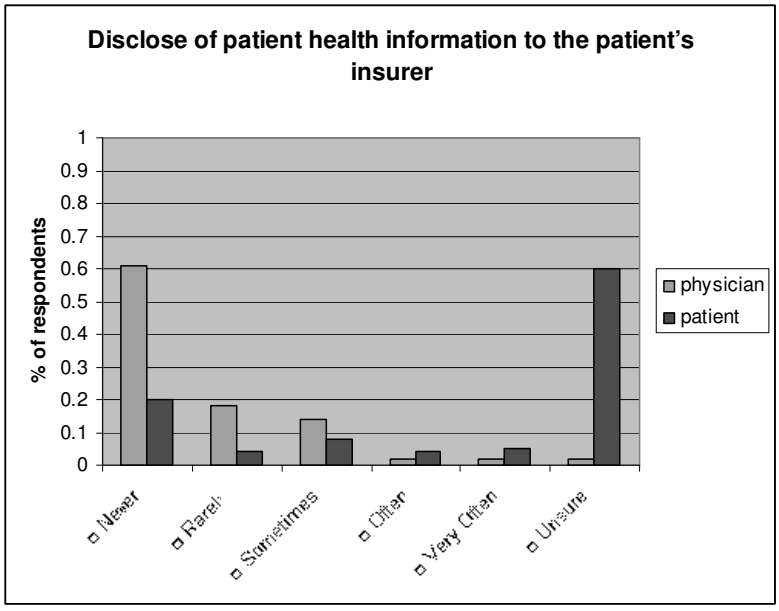

Figure B11. Privacy confidentiality/disclosure perceptions (Q11 of HIPAA).

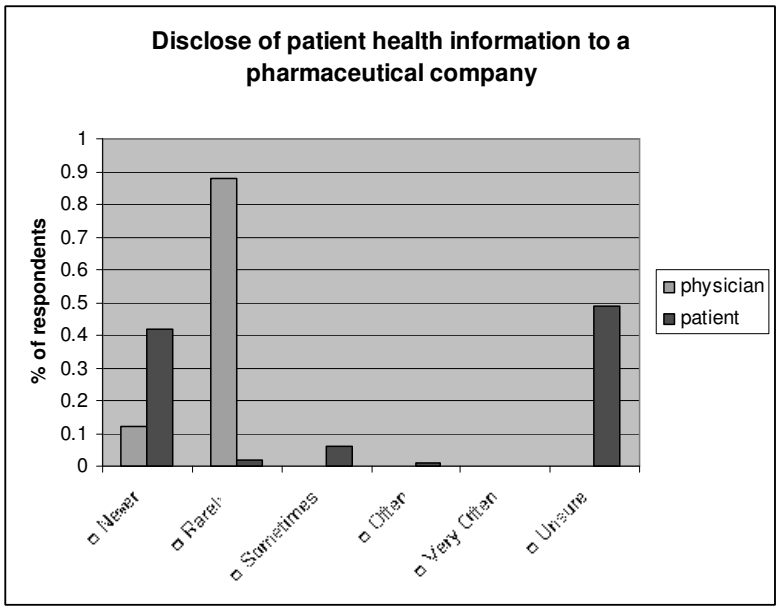

Figure B12. Privacy confidentiality/disclosure perceptions (Q12 of HIPAA).

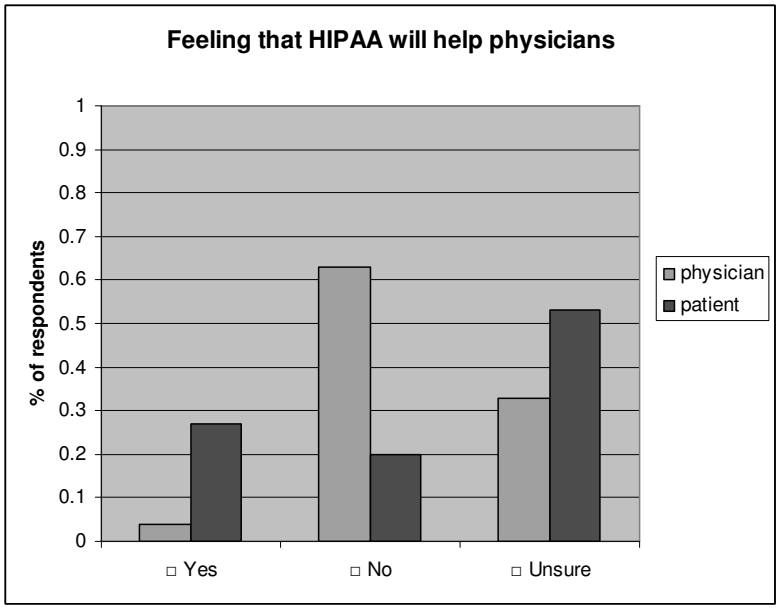

Figure B13. Privacy confidentiality/disclosure perceptions (Q15 of HIPAA).

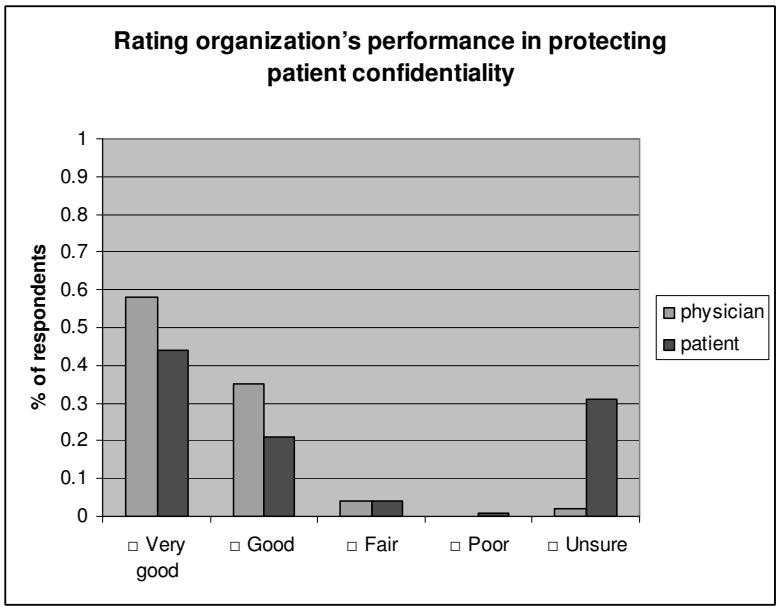

Figure B14. Privacy confidentiality/disclosure perceptions (Q16 of HIPAA).

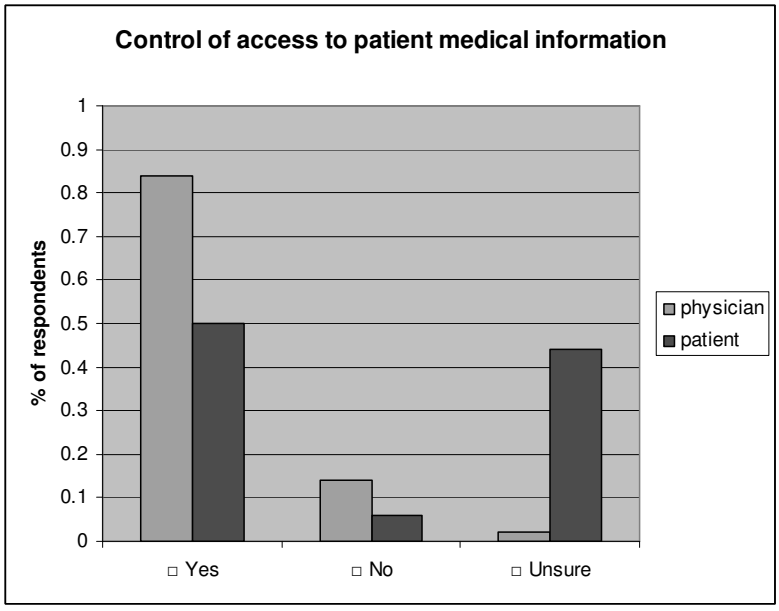

Figure B15. Privacy confidentiality/disclosure perceptions (Q19 of HIPAA).

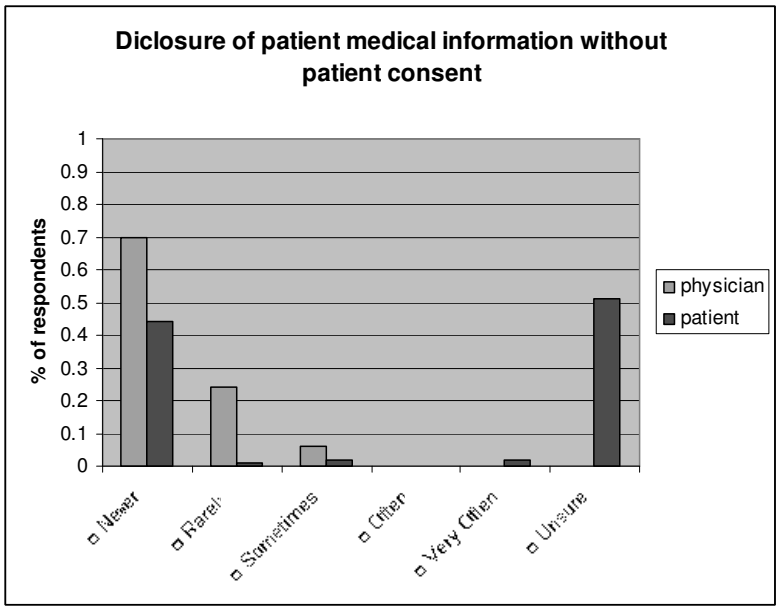

Figure B16. Privacy confidentiality/disclosure perceptions (Q20 of HIPAA).

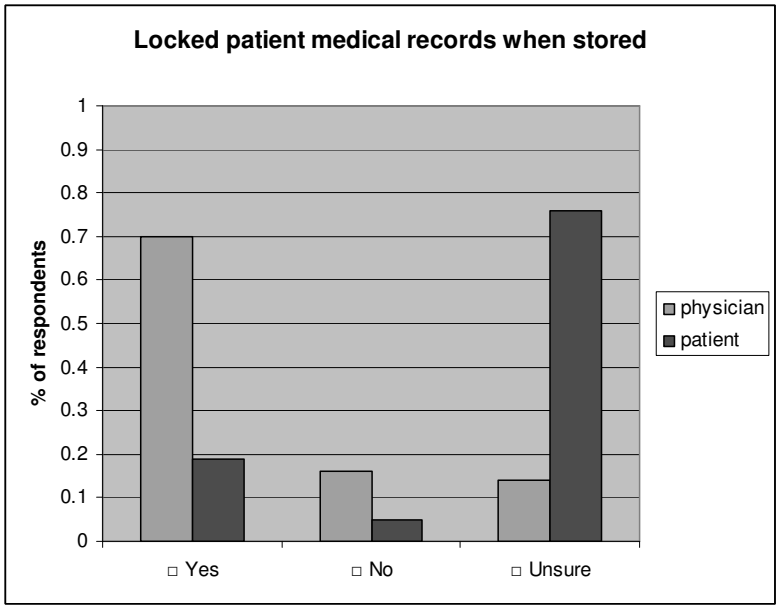

Figure B17. Privacy confidentiality/disclosure perceptions (Q21 of HIPAA).

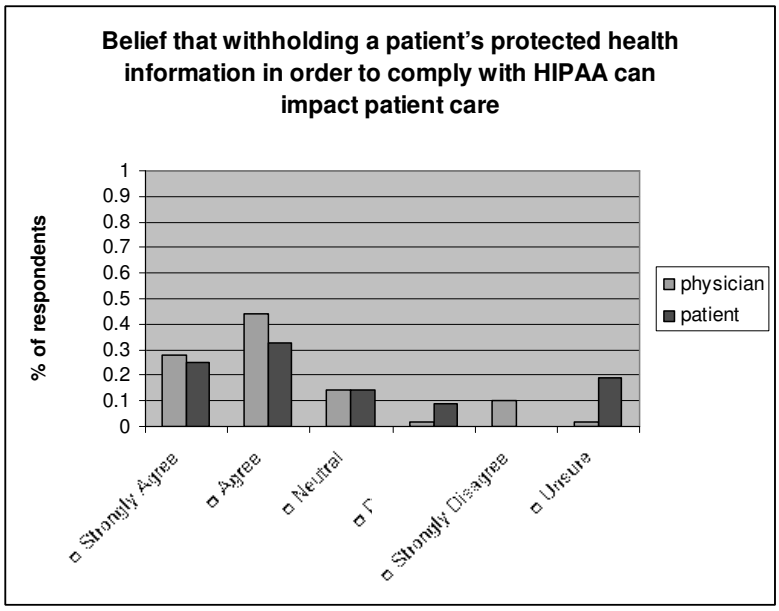

Figure B18. Patient care perceptions (Q4 of HIPAA).

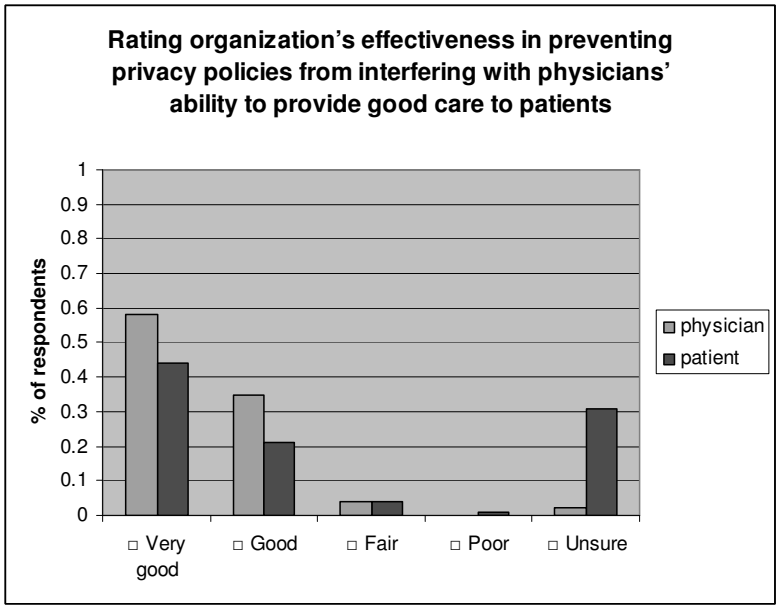

Figure B19. Patient care perceptions (Q17 of HIPAA).

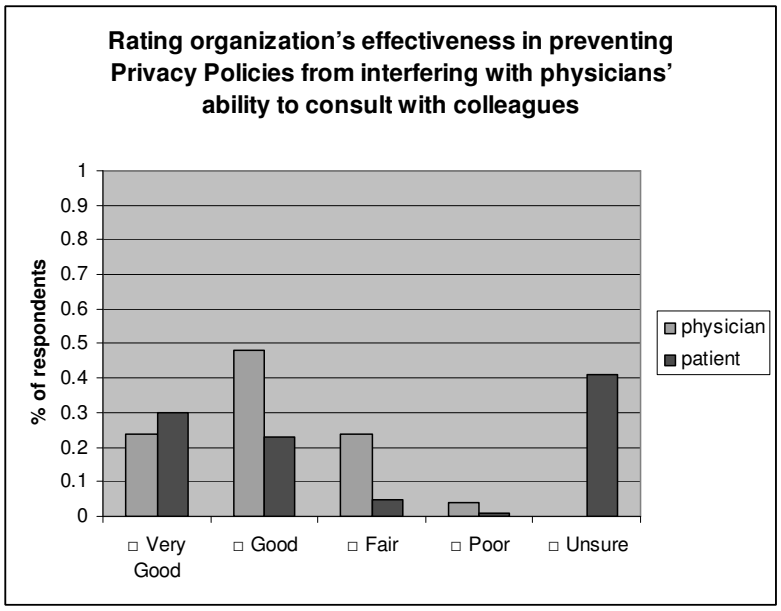

Figure B20. Patient care perceptions (Q18 of HIPAA).